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## Health of older people in Germany

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## Health in old age – status quo, challenges, and opportunities

Health monitoring of the older society is of growing socio-political relevance for several reasons. In the course of current demographic developments, a significant increase in the number of older people can be expected in the coming decades. In particular, the very old (85+ years) belong to the fastest growing group. This is accompanied by increasing morbidity at the population level, with mental and neurodegenerative diseases in old age, such as dementia, being the most common [1]. The trend, that the need for care and nursing will increase in old age, is evident [2]. Against this background, the prevention and specific treatment of common diseases among older adults, especially dementias, represent a major challenge and an important task.

Current epidemiological data and research findings on the health situation of older people are indispensable for federal health reporting in order to explore prevention and treatment potentials and thus enable specific support. The epidemiological longitudinal study *Gesundheit 65+* was launched to examine the health situation of old and very old people in Germany. In this issue, [Fuchs et al.](#) initially present the study and its objectives, contents and implementation. With *Gesundheit 65+*, a nationwide population-based health study with the target group of the German older population and a special focus on health limitations was realised for the first time to support the ongoing national health reporting. Based on this, [Gaertner et al.](#) present first study results of the baseline survey. In addition to the reported high level of life satisfaction, a number of indicators related to the living environment,

activity and participation, as well as health functions were examined, and actual data were presented by means of prevalence calculations. Their findings provide an essential starting point for the derivation of policy and practice-related recommendations for action.

The review by [Georges et al.](#) provides a comprehensive overview of demographic developments, risk factors and care options for dementia in Germany. In old age, cognitive disorders and dementia are among the most common disorders and have serious impact on individuals and the community. Consequences include increasing dependence in daily life, a growing need for support and care, institutionalisation, functional limitations, mortality, need for care as well as high costs for the health care system. In the early stages of the disease, little support may be needed, which is often provided by partners or family as informal caregivers and people who give practical assistance. As dementia progresses, caregiver resources are often exceeded and formal care (such as domestic or day care) becomes necessary to ensure that care needs are met. According to the latest predictions by the German Federal Statistical Office and only because of aging, the number of people in need of care in Germany will increase from around 5.0 million at the end of 2021 to around 6.8 million in 2055 (by 37%). Most of the increase by 2055 will be attributable to very old people aged 80 and older in need of long-term care [2].

While in Germany and worldwide the number of people with dementia will increase in the future, at the same time some factors hold an enormous potential for prevention.

In this course, current research has identified potentially modifiable risk factors for dementia and investigated them in the context of interventions that address different risk factors simultaneously [3, 4]. Key factors include low education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, and diabetes, as well as loneliness and social isolation in old age [5]. In a fact sheet, [Wurm et al.](#) present data on the prevalence of loneliness among older adults in Germany based on the German Ageing Survey (DEAS), a nationally representative cross-sectional and longitudinal survey of persons aged 40 years and older. Since loneliness and lack of social participation can significantly increase the risk of dementia, the observation of loneliness rates forms a substantial starting point for the initiation of preventive measures, not least against the background of the ongoing consequences of the COVID-19 pandemic [6].

Based on the German Aging Survey, [Wurm et al.](#) explore in another fact sheet the question of how many older persons in Germany hold an advance directive and what the determinants are. An advance directive, which contains the patient's personal will regarding medical treatments and emergency situations, is of great importance in the context of care for older individuals. Regarding age effects, it has already been shown for very old GP patients aged 85 years and older that a substantial proportion have an advance directive and power of attorney for health care [7]. In contrast, this issue shows that there is room for improvement among younger old people.

Acknowledging the importance of health in old age, this issue of the Journal of Health Monitoring highlights the collaborative efforts needed to maintain and improve it.

This is precisely why the United Nations has declared 2021–2030 the Decade of Healthy Aging [8].

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# Health status of the old and very old people in Germany: results of the Gesundheit 65+ study

## Abstract

**Background:** The demographic change makes comprehensive health reporting on health at older age an important topic.

**Methods:** Gesundheit 65+ is a longitudinal epidemiological study on the health status of persons aged 65 and older in Germany. Based on a two-stage stratified random sample from 128 local population registers, 3,694 persons participated in the baseline survey between June 2021 and April 2022 (47.9% women, mean age 78.8 years). Weighted prevalences for 19 indicators of the baseline survey are presented overall and by age, sex, education and region of residence.

**Results:** Overall, 52.0% of all participants of the baseline survey reported to be in good or very good health, and 78.5% reported high or very high satisfaction with their life. This was in contrast to the large number of health/functional limitations whose prevalences ranged from 5.3% for severe visual limitations to 69.2% for multimorbidity. The health status of women was clearly worse than that of men, and the health status of persons aged 80 and older was worse than between 65 and 79 years of age. There was a clear educational gradient evident in the health status, but there were no differences between West and East Germany.

**Conclusions:** Gesundheit 65+ provides a comprehensive database for description of the health status of old and very old people in Germany, on the basis of which recommendations for action for policy and practice can be derived.

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

## 1. Introduction

In recent decades, significant changes in the population structure have become apparent throughout the world: The proportion of older people is on the rise, while the proportion of younger people is decreasing. According to the Federal Statistical Office, the proportion of the total population of Germany that is of age 65 and older has risen from 15% in 1991 to 22% in 2021; the proportion of very old people aged 85 and older has also increased [1]. It can be presumed that the proportion of older people in society will keep

increasing [2]. The current life expectancy in Germany in 2020 for women and for men is 83.2 years and 78.3 years, respectively, and will rise, albeit at a slower rate due to flu epidemics and, from March 2020, the COVID-19 pandemic [3]. Ageing is associated with a number of health challenges, including an increased likelihood of illness and a decline in physical and cognitive function. This is associated with limitations in coping with everyday life and a possible need for assistance and care [4, 5]. Accordingly, the health status of old and very old people in Germany is increasingly coming into focus. Moreover, during the COVID-19 pandemic it

## The Gesundheit 65+ Study

Extension of the ongoing RKI monitoring by including the old and very old people with functional impairments.

**Data holder:** Robert Koch Institute

**Objectives:** Core component for a comprehensive public health monitoring in the 65+ population with a focus on subjective, psychosocial, functional aspects of health and closure of existing data gaps related to the health and well-being of older people during and after the COVID-19 pandemic.

**Study design:** Longitudinal survey (baseline survey plus three follow-ups every four months; home visit examination parallel to the last follow-up).

**Statistical population:** German-speaking persons aged 65 and older who live in Germany and are registered there as their main place of residence

**Sampling:** Two-stage sampling procedure: 1) 128 randomly selected municipalities and cities nationwide, 2) stratified random sampling in the respective local population registers according to gender and two age groups (65–79, 80+ years of age).

**Survey modes (mixed-mode):** Paper-based or online questionnaire, interview by telephone or face-to-face

**Proxy participation:** Permitted

**Consent by a legal representative:** Permitted

**Sample size:** 3,694 participants, of which 2,175 were 80 years of age and older

**Total data collection period:** June 2021 to April 2023

**Data collection period of the baseline survey:** June 2021 to April 2022

For more information, please visit [www.rki.de/gesundheits65plus](http://www.rki.de/gesundheits65plus)

became clear that important information on the health status of old and very old people was not available during the pandemic [6]. Monitoring the health status of older people is therefore relevant in many respects, e.g. for planning additional health care needs, early prevention measures while ensuring equal opportunities and participation, and to future pandemic preparedness.

The ‘Global Strategy and Action Plan on Ageing and Health 2016–2020’ of the World Health Organisation (WHO) identified measures for political leaders worldwide that are necessary to ensure that all people have the opportunity to live a long and healthy life [7]. This was in preparation for the ‘United Nations Decade of Healthy Ageing (2021–2030)’ [8]. The outcome report indicated that major challenges remain to exist and that, in particular, more data on healthy ageing across the life course should be obtained. This includes information on physical and cognitive functioning and greater standardisation of measurement data [9].

In Germany, the national health goal titled ‘Healthy Ageing’ was formulated in 2012 to strengthen the physical, mental and social resources of older people, to improve the management of age-associated health problems such as multimorbidity and dementia, and to increase the quality of medical and nursing care [4, 10]. The ‘Health in Germany’ report of the Robert Koch Institute (RKI), in its chapter ‘How healthy are older people?’, highlights the major importance of recurring primary data surveys through representative sampling as a way to allow conclusions to be drawn on diseases and functional limitations and impairments in everyday life [5].

The health status at old age comprises various components that can be described through standardised mea-

asures (indicators) [11]. These indicators should be formulated appropriately such that they not only ensure a one-time description of the status, but are able to map changes over a period of time. Based on the models of the WHO and the International Classification of Functioning, Disability and Health (ICF), a concept for the classification of indicators was developed within the framework of the ‘Improving Health Monitoring in Old Age (IMOA)’ project funded by the Robert Bosch Foundation from 2016 to 2018, which includes the health areas of ‘environmental factors’, ‘activities and participation’ and ‘personal factors (i.e. health/functional resources)’. In these health areas, a set of indicators for description of the health status for the age group 65+ years was developed in a multi-stage structured consensus process, in which an interdisciplinary committee of experts was involved [12]; the following presentation is based on this set of indicators.

Gesundheit 65+ (see [Study on Health of Older People in Germany \(‘Gesundheit 65+’\): objectives, design and implementation](#)) [13] and its baseline survey provide a data set that can be used to represent some of the core indicators described in IMOA as well as other relevant indicators (e.g. visual, hearing and mobility impairments). This will contribute to the description of the health status of older people in Germany at the time of the COVID-19 pandemic, including their health resources and risks.

## 2. Methods

### 2.1 Study design and sampling

As part of the RKI’s health monitoring programme, the nationwide, population-based, longitudinal epidemiological



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## Gesundheit 65+ is a study on the health status of old and very old people in Germany, and also includes functionally impaired older people.

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study titled Gesundheit 65+ (Health 65+) was conducted between June 2021 and April 2023 to collect representative data on the health status of old and very old people in Germany during the COVID-19 pandemic (Infobox). The target population comprised permanent residents of Germany aged 65 and older. People with insufficient knowledge of the German language and people who had died or moved away before the start of the study or were untraceable were excluded from the study. Participation was thus possible regardless of the health status of the invited person, e.g. persons in nursing homes or with limited capacity to provide consent were included. In order to also include old and very old people with functional limitations in the study, a study design that was previously tested for this age group was used for contacting and data collection [14, 15]. The baseline survey of the study was conducted using a mixed-mode survey design of data collection modes (paper/online questionnaire, interview on the phone or during a home visit) between June 2021 and April 2022. In order to reduce barriers to participation in the study, assistance in participating by relatives or other close persons or proxy-participation was permitted. For a detailed description of the study including the longitudinal data collection with three follow-ups and a home visit examination over a period of 12 months after baseline, see elsewhere [13].

The sampling was conducted in a two-stage, stratified cluster sampling procedure. In the first stage, 128 primary sampling units (PSUs) were drawn at random from all municipalities in Germany. In the second stage, within the PSUs, sex- and age-stratified random samples of the population in the age groups 65 to 79 years and 80 years and older were then drawn from the local registration registers.

The contacting of the drawn individuals for the baseline survey and thus for study participation was done according to the previously developed and tested sequential mixed-mode design [14]: written, telephone and face-to-face. Since non-contacts were visited on site in the last step of contacting and this was not feasible in terms of personnel in all PSUs at the same time, the 128 PSUs were randomly assigned into 32 routes with four PSUs each. These routes were then scheduled in an approx. 9-month route plan and persons were invited to participate in the study successively according to this plan. However, due to the pandemic in November 2021, face-to-face contacting and interviews had to be discontinued. A total of 12,248 people were invited to participate in Gesundheit 65+, and 7,904 of the invited persons were 80 years of age or older. Of those invited, 307 had to be excluded from participation in the study for the reasons mentioned above. According to the 'Standards of the American Association for Public Opinion Research' [16], the response rate 2 (i.e. including partial surveys) was 30.9% as a total of 3,694 persons participated in the baseline survey. The majority of the participants participated by paper-based questionnaires (86.2%) followed by online questionnaires (7.5%), face-to-face interviews (4.1%) and telephone (2.2%) interviews. In total, there were 327 proxy-participations.

### 2.2 Indicators

The content of the baseline survey included essential health concepts for old and very old people from the health areas of environmental factors, activities/participation and health/functional resources [17]. The selection of indicators

was based, to the extent possible, on the health indicators for the population aged 65 and older previously developed in IMOA [12] and supplemented to include other important topics related to the health of older people (e.g. visual, hearing and mobility impairments). In order to lower the barriers to participation for very old or functionally impaired persons, the effort involved in responding in the survey was minimised as far as possible and, e.g. extensive instruments were not administered.

#### Environmental factors

Receiving long-term care benefits (Pflegegrad) was recorded by asking ‘Do you have a degree of care?’, and the responses were summarised in two categories (yes vs. no or application is pending). Regarding the provision of care to another person in the form of informal lay care, the participants were asked whether they ‘currently took care of or looked after a person in need of care or who is seriously ill’ (yes vs. no). Social support was measured with the Oslo-3 Social Support Scale [OSS-3, 18], a three-question instrument assessing the number of close persons, concern and interest of other people, and receiving practical help from neighbours (range of the total score: 3 to 14). A total score of less than 9 was considered as low level of support (yes vs. no) [19]. Loneliness was assessed with the three-question Revised UCLA Loneliness Scale instrument [R-UCLA, 20, 21], which queried lacking companionship, feeling left out and feeling isolated from others (range of total score: 3 to 9). Loneliness was defined by a total score of 6 or more (yes vs. no) [22].

#### Activities/participation

Limitations in activities of daily living were assessed through internationally established instruments of the European Health Interview Survey (EHIS) [23]. Five basic activities of daily living (intake of food, getting up or sitting down, dressing and undressing, using toilets, personal hygiene) were recorded following Katz et al. [24]. In addition, seven instrumental activities of daily living (preparing meals, using the telephone, going shopping, organising medication intake, doing light housework, doing occasional heavy housework, taking care of finances and everyday administrative tasks) were used following Lawton and Brody [25]. For each activity, the participants were asked whether they would normally have difficulty performing that activity without assistance (response categories: no, some, a lot of difficulty, unable to do; additional category for instrumental activities only: not applicable (never tried or done this). If a lot of difficulty or impossibility to carry out the activity was reported at least once, this was defined to be a limitation in basic or instrumental activities of daily living (yes vs. no). The additional response category of ‘not applicable’ was not counted as a limitation, and two missing values each were permitted.

#### Health/functional resources

The self-perceived general health was recorded by asking ‘How is your health in general?’ (response categories: very good, good, fair, bad, very bad) [26, 27]. For the analyses, the response categories ‘good’ and ‘very good’ were combined and compared to the other three categories. Self-reported 12-month prevalences of ten different age-relevant chronic diseases and health problems were recorded based

on a list according to the EHIS [23]. These diseases and health problems comprised 1. Hypertension (high blood pressure), 2. Coronary heart disease (incl. myocardial infarction or chronic symptoms secondary to myocardial infarction, angina pectoris), 3. Stroke (incl. chronic symptoms secondary to a stroke), 4. Hypercholesterolaemia (high blood lipids), 5. Diabetes, 6. Chronic bronchitis (incl. chronic obstructive pulmonary disease, emphysema), 7. Arthrosis, 8. Osteoporosis, 9. Lower back disorder or other chronic back defect, and 10. Depression. In addition, cancer was recorded by asking ‘Has a doctor ever diagnosed you with cancer?’ First, the total sum of the prevalent diseases and health problems was calculated from the responses given (range: 0 to 11). Up to seven missing values were permitted, as it was assumed that in the selected list format, diseases which the participants were not afflicted by or which were unknown to them often remained without a response. Multimorbidity was defined as the presence of two or more diseases and health problems (yes vs. no) [28]. Depressive symptoms in the past two weeks were assessed with the two-question Patient Health Questionnaire (PHQ-2) instrument [29] on symptoms of little interest or pleasure in doing things, as well as feeling down, depressed or hopeless (range of total score: 0 to 6). A total score of 3 or more was considered to indicate depressive symptoms (yes vs. no). General satisfaction with life was assessed by asking ‘How satisfied are you, all things considered, with your life at present?’ (response categories: 0 – completely dissatisfied to 10 – completely satisfied) following Richter [30]. Any score of 7 or more was considered to indicate high or very high satisfaction with life [12].

Sensory and mobility limitations were recorded according to the EHIS [23] using five questions: one question on vision, two questions on hearing and two questions on mobility. The response categories were identical for all questions (no, some, a lot of difficulty, unable to do). If participants reported at least a lot of difficulty in their vision even with glasses or contact lenses, this was defined as severe visual impairment. The coding for severe hearing or mobility impairments was done accordingly. Persons who reported at least a lot of difficulty hearing a conversation with another person (with a hearing aid, if applicable) in either a quiet (1st question) or noisier room (2nd question) were coded as experiencing severe hearing impairment. Mobility impairment was considered if the person reported difficulty walking half a kilometre on level ground without a walking aid (1st question) or walking up or down 12 steps (2nd question). For all other responses or response combinations, no impairments were assumed.

Pain was recorded by asking about the intensity of pain during the past four weeks (response categories: none, very mild, mild, moderate, severe, very severe) [31]. Participants reporting pain were asked how long the pain had been persisting [32]. Chronic pain was assumed if severe or very severe pain for at least six months was reported. Falls were recorded according to the recommendations of the PROFANE network [33] by asking ‘Have you fallen, tripped or slipped so that you lost your balance and landed on the ground or a lower level during the past 12 months?’. In the analyses, the next question on the number of falls was used to construct two variables, i.e. whether the participant had fallen at least once or at least twice (yes vs. no in each case). Urinary incontinence in the past 12 months

(yes vs. no) was evident if participants reported urinary incontinence or problems controlling their bladder [23]. Faecal incontinence was recorded by asking ‘Have you had difficulty holding or controlling your bowel movements in the past four weeks? (yes vs. no). Subjective memory impairment was evident if the participants reported worsening of their memory and were worried about it [34].

### 2.3 Stratification variables

Information on gender, month and year of birth was provided from the registration data by the local population registers at the time of sampling. With regard to gender, the provision of a third gender was permitted, but no one used this option, so that a stratification for women and men was done in the analyses. Age in years was calculated using the date of birth and the day of participation in the survey. Two age groups were defined (65 to 79 vs. 80 years and older). There are several established classifications for determining the level of education [vgl. 35]. For the following analyses, the Comparative Analyses of Social Mobility in Industrial Nations (CASMIN) classification [36, 37] was chosen to represent the educational level, as this classification maps the specifics of the German tripartite school system quite well for the analyses and if applicable may better identify social inequalities. The CASMIN classification distinguishes between low education (i.e. primary and low secondary education), medium education (i.e. intermediate/high secondary education) and high education (i.e. tertiary education) on the basis of the highest level of school and vocational/professional education attained [vgl. auch 38]. In order to map regional differences, the region

of residence variable distinguished between the federal states of West and East (incl. Berlin) Germany.

### 2.4 Statistical analysis

First, absolute numbers and percentages were calculated for a sample description overall and by gender. Then, prevalences and 95% confidence intervals (95% CI) of all health indicators were calculated overall and by the specified stratification variables and presented in a table or figure. Prevalences are estimates of the percentage of affected persons in the target group at a given time. Their precision can be assessed using confidence intervals – broad confidence intervals indicate greater statistical uncertainty of the results. Since subjective assessments were required for some indicators (i.e. loneliness, depressive symptoms, satisfaction with life and subjective memory impairment), only self-reported data from the invited individual and no data from proxies were taken into account for these indicators in the analyses.

A weighting factor was calculated in order to correct the prevalences for deviations of the study participants from the target population of people aged 65 and older in Germany as of 31st December 2020 with regard to gender, age, region and municipality size according to the BIK-10 classification [39]. In addition, the weighting factor took into account deviations in the level of education compared to the resident population of Germany based on the 2018 Microcensus according to the International Standard Classification of Education (ISCED classification) [40].

All analyses were conducted using Stata/SE 17.0 (Stata Corp., College Station, TX, USA, 2017). In order to appropriately account for clustering by PSUs and the weighting,

**A total of 78.5 % of people aged 65 and older in Germany are very satisfied with their lives and every second person rates their own health as good or very good.**

all analyses were conducted using survey procedures. A statistically significant difference between groups is assumed to exist when confidence intervals do not overlap. All differences that are significant according to this definition are reported in the results section.

### 3. Results

#### 3.1 Description of the baseline sample

Of the 3,694 participants in the baseline survey of Gesundheit 65+, 47.9 % were women and 58.9 % were 80 years of age or older (Table 1). On average, the participants were 78.8 years of age and the maximum age was 100 years. A total of 49.2 % of all participants had a low educational level and 23.5 % a high educational level. A total of 19.3 % of the participants resided in East Germany.

	Total (n=3,694)	Women (n=1,771)	Men (n=1,923)
<b>Age group – % (n)</b>			
65–79 years	41.1 (1,519)	40.8 (722)	41.5 (797)
80+ years	58.9 (2,175)	59.2 (1,049)	58.6 (1,126)
<b>Age (years)</b>			
Mean (standard deviation)	78.8 (7,5)	79.0 (7,8)	78.6 (7,2)
Range	65–100	65–100	65–100
<b>Educational group – % (n)</b>			
Low	49.2 (1,793)	54.5 (954)	44.3 (839)
Median	27.3 (994)	30.5 (534)	24.3 (460)
High	23.5 (858)	15.0 (263)	31.4 (595)
<b>Region of residence – % (n)</b>			
East Germany	19.3 (714)	19.5 (345)	19.2 (369)
West Germany	80.7 (2,980)	80.5 (1,426)	80.8 (1,554)

Table 1

Sample description overall and by gender  
(n=3,694, unweighted analyses)

Source: Gesundheit 65+, own description

There was a difference between women and men with regard to education: Women were more often assigned to a low level of education (54.5 % vs. 44.3 %) than men, and less often to a high level of education (15.0 % vs. 31.4 %) than men.

#### 3.2 Health of older people in Germany according to the different health areas

The prevalences and the number of missing values of the selected health indicators are shown in Table 2 for the health areas of environmental factors, activities/participation and health/functional resources. Accordingly, the absolute number of missing values for the indicators for the 3,694 participants varied from 52 missing values on self-perceived general health to a maximum of 223 missing values on receiving long-term care benefits; i.e. the percentage of missing values ranged between 1.4 % and 6.0 %.

In the description of their environmental factors, 16.9 % of the older persons reported that they received long-term care benefits. A total of 11.8 % of the participants provided informal care to a person in need of care or who was seriously ill. Overall, 19.2 % of the older people received a low level of social support and 19.2 % felt lonely. In the field of activities/participation, 9.8 % and 20.3 % of the older people were limited in basic and instrumental activities of daily living, respectively. Concerning their health resources, 52.0 % of the older persons assessed their health as good or very good, and 78.5 % were satisfied or very satisfied with their lives. However, health and functional limitations were quite common: Multimorbidity (69.2 %), urinary incontinence (27.5 %), subjective memory impairment (27.3 %), at least one fall in the past year (24.1 %), impaired mobility

**Table 2**  
**Prevalences of health indicators overall and absolute number of their missing values (n=3,694, weighted analyses)**  
 Source: Gesundheit 65+, own description

	%	(95 % CI)	Number missing values
<b>Living environment</b>			
Degree of care	16.9	(15.3–18.7)	223
Care provided to a person	11.8	(10.3–13.4)	74
Low social support	19.2	(17.3–21.3)	204
Loneliness*	19.2	(17.3–21.2)	77
<b>Activities/participation</b>			
Limitations in basic activities of daily life	9.8	(8.6–11.2)	82
Limitations in instrumental activities of daily life	20.3	(18.6–22.2)	67
<b>Health/functional resources</b>			
(Very) good subjective health	52.0	(49.6–54.4)	52
Multimorbidity (in previous 12 months)	69.2	(66.9–71.5)	140
Depressiveness* (in previous 2 weeks)	13.5	(12.1–15.2)	89
(Very) high satisfaction with life*	78.5	(76.5–80.4)	90
Severely impaired vision	5.3	(4.6–6.3)	91
Severely impaired hearing	17.0	(15.5–18.5)	161
Impaired mobility	20.8	(18.9–22.8)	64
Chronic pain	14.3	(12.7–16.0)	143
Falls (in previous 12 months)			
≥ 1 fall	24.1	(22.3–26.1)	67
≥ 2 falls	12.9	(11.4–14.5)	103
Urinary incontinence (in previous 12 months)	27.5	(25.4–29.8)	60
Faecal incontinence (in previous 4 weeks)	9.6	(8.3–11.0)	60
Subjective deterioration of memory*	27.3	(25.1–29.7)	132

CI=confidence interval, \*=no proxy information included

**Older people are afflicted by a variety of health problems and limitations.**

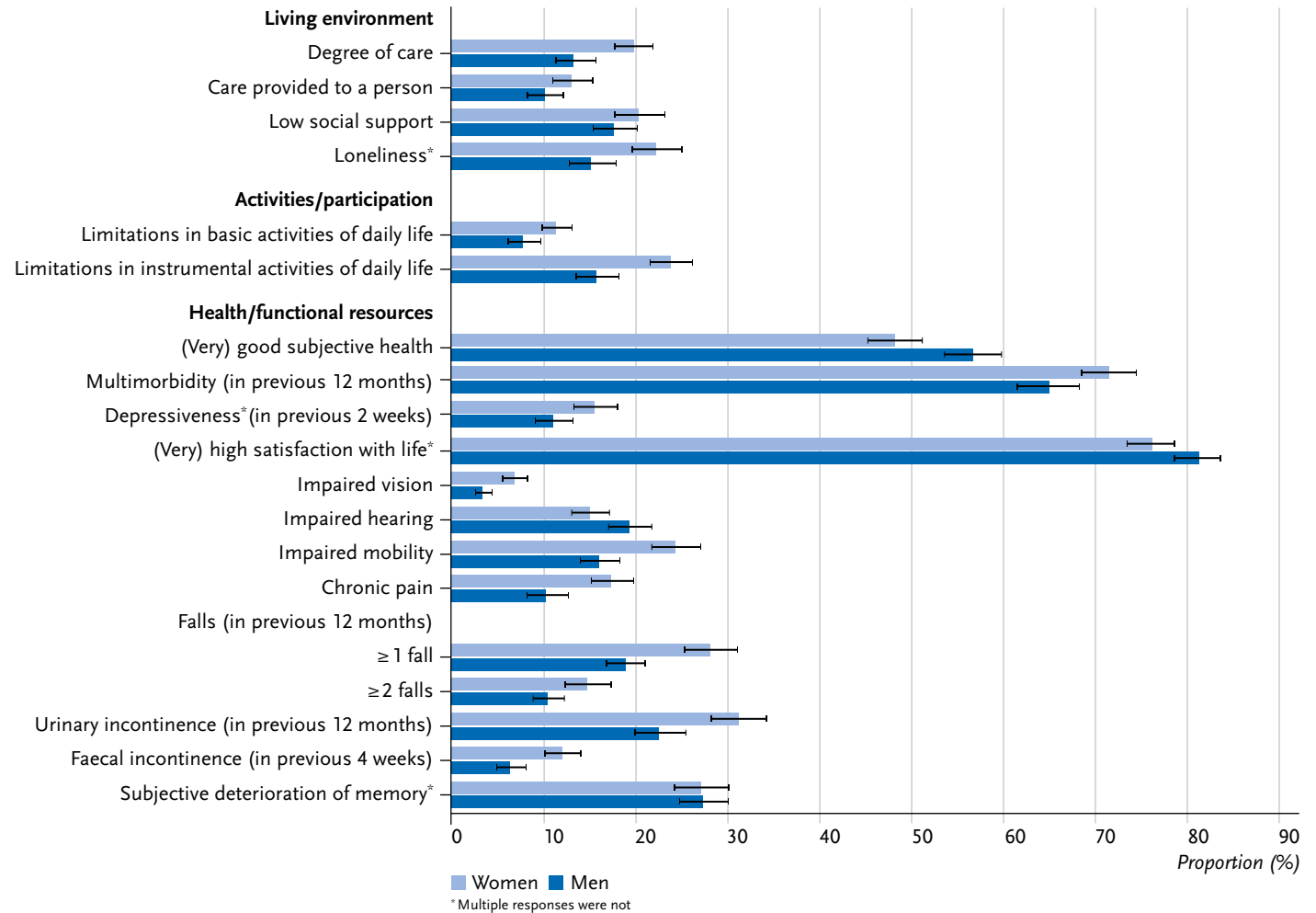
(20.8%), severe hearing impairment (17.0%), chronic pain (14.3%), depressive symptoms (13.8%), multiple falls in the past year (12.9%), faecal incontinence (9.6%) and severe visual impairment (5.3%).

### 3.3 Gender and age differences in different health status areas

Overall, women aged 65 and older rated their health worse than men (Figure 1). Accordingly, they reported urinary

incontinence (31.4% vs. 22.6%), at least one fall in the past year (28.2% vs. 19.0%), impaired mobility (24.4% vs. 16.1%), limitations in instrumental activities of daily living (23.9% vs. 15.8%), loneliness (22.3% vs. 15.2%), receiving long-term care benefits (19.9% vs. 13.3%), chronic pain (17.4% vs. 10.3%), depressive symptoms (15.6% vs. 11.1%), multiple falls in the past year (14.8% vs. 10.5%), faecal incontinence (12.1% vs. 6.4%), limitations in basic activities of daily living (11.4% vs. 7.8%) and severe visual impairments (6.9% vs. 3.4%) more often than men.

**Figure 1**  
**Prevalences and 95 % confidence intervals**  
**of health indicators by gender**  
 (n=3,694, weighted analyses, numbers are in %)  
 Source: Gesundheit 65+, own description



Correspondingly, men reported good or very good subjective health more often than women (56.8% vs. 48.3%).

Table 3 provides an overview of the health status stratified by gender and age groups. The health status of very old persons aged 80 and older was clearly worse compared to the younger age group of 65 to 79 years of age (Table 3).

In some cases, the prevalences were several times higher in the older age group than in the younger age group (e.g. 6.1% of the 65- to 79-year-old and 44.3% of the 80-year-old and older women received long-term care benefits, respectively). This applied equally to both women and men with regard to receiving long-term care benefits, limitations

**Table 3**  
Prevalences of health indicators  
by gender and age  
(n=3,694, weighted analyses)

Source: Gesundheit 65+, own description

Age group	Women				Men			
	65–79 years (n=722)		80+ years (n=1,049)		65–79 years (n=797)		80+ years (n=1,126)	
	%	(95% CI)	%	(95% CI)	%	(95% CI)	%	(95% CI)
<b>Living environment</b>								
Degree of care	6.1	(4.3–8.7)	44.3	(40.1–48.6)	8.0	(5.7–11.1)	26.9	(23.2–30.9)
Care provided to a person	16.0	(13.0–19.6)	7.7	(5.9–10.0)	10.9	(8.5–14.0)	8.2	(6.5–10.3)
Low social support	18.4	(15.1–22.3)	24.1	(20.6–27.9)	17.6	(14.5–21.1)	18.1	(15.4–21.2)
Loneliness*	19.4	(16.0–23.3)	29.0	(25.1–33.2)	14.4	(11.5–17.9)	17.5	(14.6–20.8)
<b>Activities/participation</b>								
Limitations in basic activities of daily life	2.9	(1.8–4.7)	27.0	(23.3–31.1)	4.9	(3.2–7.5)	15.3	(12.7–18.3)
Limitations in instrumental activities of daily life	10.1	(7.7–13.3)	48.7	(44.1–53.2)	10.4	(8.0–13.5)	29.7	(25.5–34.3)
<b>Health/functional resources</b>								
(Very) good subjective health	57.8	(53.5–62.0)	31.0	(27.6–34.7)	62.5	(58.4–66.4)	42.4	(39.0–45.8)
Multimorbidity (in previous 12 months)	66.2	(61.9–70.3)	82.4	(79.1–85.3)	63.6	(59.1–67.9)	70.9	(67.4–74.1)
Depressiveness* (in previous 2 weeks)	13.8	(11.0–17.3)	19.6	(16.3–23.3)	9.4	(7.1–12.3)	15.8	(12.7–19.4)
(Very) high satisfaction with life*	78.2	(74.5–81.4)	71.9	(67.6–75.8)	83.8	(80.1–86.8)	74.4	(70.5–78.1)
Severely impaired vision	2.6	(1.5–4.5)	14.6	(12.0–17.7)	1.8	(1.0–3.1)	7.5	(5.6–10.1)
Severely impaired hearing	7.1	(5.1–10.0)	29.4	(25.6–33.6)	15.2	(12.5–18.4)	30.0	(26.6–33.6)
Impaired mobility	10.3	(7.7–13.7)	49.9	(45.4–54.4)	10.1	(7.9–13.0)	31.2	(27.7–35.1)
Chronic pain	14.8	(11.8–18.4)	22.2	(19.2–25.6)	8.4	(5.9–11.9)	14.9	(12.1–18.2)
Falls (in previous 12 months)								
≥ 1 fall	21.0	(17.6–24.8)	41.2	(36.9–45.7)	14.0	(11.4–16.9)	31.8	(28.7–35.1)
≥ 2 falls	8.6	(6.2–11.8)	26.0	(21.9–30.5)	7.2	(5.3–9.8)	19.0	(16.3–22.0)
Urinary incontinence (in previous 12 months)	21.9	(18.1–26.3)	48.4	(43.9–52.9)	18.0	(15.0–21.5)	34.5	(30.7–38.4)
Faecal incontinence (in previous 4 weeks)	7.9	(5.7–10.7)	19.7	(16.7–23.1)	3.8	(2.5–5.8)	12.9	(10.4–15.8)
Subjective deterioration of memory*	25.0	(21.6–28.8)	32.2	(28.0–36.6)	25.6	(22.3–29.1)	32.7	(29.0–36.6)

CI=confidence interval, \* = no proxy information included

**Especially women and persons aged 80 and older or those with low educational level report health problems and limitations particularly frequently.**

in basic and instrumental activities of daily living, subjective health status, limitations in sensory and mobility, chronic pain, fall events and urinary and faecal incontinence. With regard to depressive symptoms and lower life satisfaction, this only applied to men, and with regard to loneliness and multimorbidity, only to women. Women of very old age were also less likely to care for another person informally than younger women.

### 3.4 Educational differences in different health areas

There was a clear educational gradient in the health status in old age (Table 4). Older women and men with a low level of education, and to some extent also with a medium educational level, reported health problems more frequently than those with a high educational level. Occasionally, the prevalences were several times higher among those



**Table 4**  
Prevalences of health indicators  
by gender and education  
(n=3,645, weighted analyses)

Source: Gesundheit 65+, own description

Educational group <sup>♦</sup>	Women						Men					
	Low (n=954)		Middle (n=534)		High (n=263)		Low (n=839)		Middle (n=460)		High (n=595)	
	%	(95 % CI)	%	(95 % CI)	%	(95 % CI)	%	(95 % CI)	%	(95 % CI)	%	(95 % CI)
<b>Living environment</b>												
Degree of care	25.9	(22.8–29.3)	12.7	(9.7–16.5)	6.7	(4.0–10.9)	18.1	(14.5–22.3)	11.6	(8.2–16.1)	4.8	(3.4–6.9)
Care provided to a person	12.8	(10.0–16.2)	13.5	(9.9–18.1)	12.5	(8.2–18.6)	8.0	(5.8–10.9)	12.6	(8.5–18.3)	9.9	(7.1–13.6)
Low social support	23.4	(19.5–27.8)	16.8	(12.8–21.7)	12.2	(7.8–18.7)	19.5	(15.6–24.0)	18.7	(14.3–24.1)	12.7	(9.6–16.7)
Loneliness*	22.8	(19.3–26.8)	22.4	(18.0–27.6)	18.4	(12.7–25.9)	15.2	(11.7–19.6)	18.4	(14.1–23.7)	9.8	(7.4–12.9)
<b>Activities/participation</b>												
Limitations in basic activities of daily life	14.9	(12.4–17.7)	7.3	(5.3–10.0)	3.2	(1.6–6.2)	11.0	(8.1–14.8)	6.8	(4.5–10.2)	2.4	(1.3–4.3)
Limitations in instrumental activities of daily life	29.7	(26.5–33.1)	16.5	(12.8–21.0)	10.5	(7.3–15.0)	21.8	(17.9–26.2)	13.0	(9.7–17.2)	6.8	(4.8–9.4)
<b>Health/functional resources</b>												
(Very) good subjective health	43.7	(39.3–48.2)	52.4	(46.7–58.0)	65.0	(56.4–72.8)	46.8	(41.5–52.2)	61.3	(55.7–66.5)	72.9	(67.7–77.6)
Multimorbidity (in previous 12 months)	74.9	(70.8–78.7)	67.8	(61.8–73.2)	70.9	(64.1–76.8)	69.5	(64.3–74.2)	63.5	(57.0–69.5)	62.2	(56.5–67.6)
Depressiveness* (in previous 2 weeks)	16.6	(13.2–20.6)	15.0	(11.4–19.5)	13.1	(8.6–19.4)	14.2	(11.2–17.9)	11.6	(8.0–16.6)	3.9	(2.1–7.1)
(Very) high satisfaction with life*	75.8	(71.7–79.5)	74.8	(69.9–79.2)	81.9	(75.0–87.2)	79.8	(75.8–83.3)	77.5	(71.2–82.8)	90.5	(87.4–92.9)
Severely impaired vision	8.3	(6.5–10.5)	5.8	(4.0–8.2)	1.9	(1.1–3.5)	4.0	(2.8–5.8)	3.8	(2.3–6.2)	1.5	(0.8–2.8)
Severely impaired hearing	16.3	(13.6–19.4)	14.4	(11.1–18.6)	9.7	(6.1–15.1)	22.4	(19.1–26.1)	17.6	(13.5–22.7)	15.8	(12.0–20.5)
Impaired mobility	30.7	(26.8–35.0)	16.6	(13.2–20.7)	10.2	(6.8–14.9)	21.4	(17.7–25.8)	13.4	(9.9–17.8)	8.3	(5.8–11.7)
Chronic pain	19.0	(15.7–22.9)	17.2	(13.2–22.2)	7.5	(4.2–13.0)	12.8	(10.1–16.2)	8.2	(5.4–12.3)	7.7	(4.3–13.4)
Falls (in previous 12 months)												
≥ 1 fall	28.3	(24.8–32.1)	29.2	(24.7–34.2)	26.5	(20.8–33.3)	20.7	(17.8–24.0)	17.2	(12.6–22.9)	17.6	(14.4–21.4)
≥ 2 falls	15.8	(12.8–19.5)	14.6	(11.6–18.2)	9.5	(6.0–14.8)	12.5	(10.0–15.6)	8.7	(5.7–13.0)	9.1	(6.6–12.2)
Urinary incontinence (in previous 12 months)	33.1	(29.3–37.2)	28.2	(23.1–34.0)	28.2	(20.6–37.3)	26.9	(22.7–31.5)	19.6	(15.1–24.9)	18.3	(15.0–22.3)
Faecal incontinence (in previous 4 weeks)	13.9	(11.1–17.3)	9.6	(7.0–13.0)	9.1	(5.5–14.7)	7.4	(5.0–11.0)	5.9	(3.9–8.7)	4.5	(2.9–7.1)
Subjective deterioration of memory*	28.8	(24.5–33.4)	24.1	(19.9–28.8)	30.9	(24.8–37.8)	27.5	(23.7–31.7)	29.5	(23.7–36.0)	24.5	(20.5–29.1)

CI=confidence interval, \*=no proxy data included,

<sup>♦</sup>Classification Comparative Analyses of Social Mobility in Industrial Nations (CASMIN) Classification based on the highest level of education and training attained. A low education group was assigned if the respondent reported at most a lower secondary school-leaving certificate, but no vocational qualification

**There are no regional differences evident in the health status of the older people in a comparison of West and East Germany.**

with a low educational level than with a high educational level (e.g. 6.7% of the women with a high educational level and 25.9% of the women with a low educational level received long-term care benefits, respectively). This applied equally to both women and men with regard to receiving long-term care benefits, limitations in basic and instrumental activities of daily living, subjective health status, severe visual and mobility impairments. With regard to loneliness, depressive symptoms, lower life satisfaction and urinary incontinence, an educational gradient was only detected for men, whereas the same applied to low social support and chronic pain only for women.

### 3.5 Living in West vs. East Germany and health of older persons in different health areas

No regional differences in the health of older persons by residence in West or East Germany were detected (Table 5). The prevalences of the selected health indicators differed between West and East Germany by a maximum of 3.5%, i.e. in the case of subjective health status. None of the differences was statistically significant.

	Region of residence			
	West Germany (n=2,980)		East Germany (n=714)	
	%	(95% CI)	%	(95% CI)
<b>Living environment</b>				
Degree of care	16.6	(15.0–18.4)	18.0	(14.0–23.0)
Care provided to a person	12.0	(10.4–13.8)	11.1	(8.0–15.2)
Low social support	18.8	(16.6–21.2)	20.8	(16.8–25.5)
Loneliness*	19.0	(17.1–21.1)	19.7	(14.8–25.7)
<b>Activities/participation</b>				
Limitations in basic activities of daily life	9.5	(8.3–10.9)	10.9	(8.1–14.6)
Limitations in instrumental activities of daily life	20.7	(18.8–22.7)	19.2	(15.2–23.9)
<b>Health/functional resources</b>				
(Very) good subjective health	52.8	(50.2–55.3)	49.3	(43.6–54.9)
Multimorbidity (in previous 12 months)	68.5	(65.8–71.2)	71.6	(67.0–75.9)
Depressiveness* (in previous 2 weeks)	13.1	(11.6–14.9)	14.9	(11.6–19.0)
(Very) high satisfaction with life*	78.7	(76.4–80.9)	77.8	(73.6–81.6)
Severely impaired vision	5.5	(4.7–6.6)	4.7	(3.1–6.8)
Severely impaired hearing	16.8	(15.3–18.5)	17.5	(14.0–21.8)
Impaired mobility	20.6	(18.5–22.9)	21.4	(17.6–25.9)

CI=confidence interval, \*=no proxy information included

Continued on next page

**Table 5**  
**Prevalences of health indicators**  
**by Region of residence**  
**(n=3,694, weighted analyses)**

Source: Gesundheit 65+, own description

**Table 5 Continued**  
**Prevalences of health indicators**  
**by Region of residence**  
**(n=3,694, weighted analyses)**

Source: Gesundheit 65+, own description

	Region of residence			
	West Germany (n=2,980)		East Germany (n=714)	
	%	(95% CI)	%	(95% CI)
<b>Health/functional resources</b>				
Chronic pain	13.9	(12.2–15.7)	15.8	(12.1–20.3)
Falls (in previous 12 months)				
≥ 1 fall	24.1	(22.0–26.3)	24.2	(20.4–28.4)
≥ 2 falls	12.8	(11.1–14.7)	13.2	(10.3–16.8)
Urinary incontinence (in previous 12 months)	28.2	(25.8–30.8)	25.1	(20.9–29.9)
Faecal incontinence (in previous 4 weeks)	10.2	(8.7–12.0)	7.1	(5.3–9.5)
Subjective deterioration of memory*	26.8	(24.4–29.4)	28.9	(23.5–34.9)

CI=confidence interval, \* = no proxy information included

#### 4. Discussion

Gesundheit 65+ is the first nationwide health survey including an examination of the population aged 65 and older in Germany, with special consideration of the very old people and persons with health impairments. The present analyses sheds light on the health status of older women and men in Germany during the COVID-19 pandemic from June 2021 to April 2022 on the basis of the population-representative baseline survey. Overall, 78.5% of the participants were very satisfied with their lives and every second woman and man assessed their own health as good or very good. This contrasts with a large number of health limitations being reported; the phenomenon is described in the literature as a ‘well-being paradox’ and is presumably based on adaptation strategies of the older people [41]. However, with regard to subjective health status as well as health impairments and receiving long-term care benefits, there are considerable gender differences and according to education, which become even more pronounced beyond the

age of 80. Our data revealed a noticeably higher prevalence of receiving long-term care benefits compared to the presence of limitations in basic activities of daily living (16.9% vs. 9.8%). This can be explained by the fact that more and different criteria (e.g. communication skills, mental disorders, cognitive impairments) are used in the determination of long-term care benefits. Furthermore, no regional differences between West and East Germany were detected in Gesundheit 65+.

The age- and gender-specific differences in health status described are essentially consistent with those from other national and international studies. Overall, women rate their health as worse and report more health problems than men, but they live longer. These differences, also known as the gender paradox, have been known for many years [42–46] and can also be found in recent studies [47–51]. The underlying reasons are varied and complex, and are attributed to both biological (sex) and social (gender) factors, with no underlying monocausal relationship [52]. Comparing the participants of Gesundheit 65+ it was evi-

dent that women were more likely to be less educated than men. The gender differences detected are thus partly due to the unequal social status, as has been discussed since the mid-1990s [53–55].

Health inequalities in old age in Germany have been described previously by other authors [56–59]. Gesundheit 65+ also shows health inequalities by educational level for older age in Germany, some of which pertain to both sexes (receiving long-term care benefits, self-rated general health, limitations in activities of daily living, impairments of vision and mobility), some only to women (low social support, chronic pain) or only to men (loneliness, depressive symptoms, low satisfaction with life, urinary incontinence). Participants with a high level of education had fewer health problems than those with a low level of education. The extent to which these differences pre-existed in the present sample before reaching older age and are persisting, increasing or decreasing in this phase of life cannot be clarified with this cross-sectional analysis of the baseline survey of Gesundheit 65+. In addition to longitudinal analyses to address this issue, it would also be necessary in the future to consider other aspects of the social status, such as poverty risk, which pertains to women in particular [60], and other indicators of social inequality in further analyses.

In the following, selected results are discussed that provide a deeper insight into the lives of older and very old people, especially during the COVID-19 pandemic, and thus indicate which topics should be given greater attention, also with regard to future pandemics. Since Gesundheit 65+ was conducted only during the time of the COVID-19 pandemic and no pre-pandemic data on participants

being available, it is not possible to assess the effects of the pandemic on the health status of older people in Germany.

Psychosocial health was an important topic during the COVID-19 pandemic. At the beginning of the pandemic, older people were in focus as a high-risk group, not only in Germany; especially with regard to negative indirect health consequences of the containment measures (distancing, contact reduction, discontinuation of social activities) such as social isolation, loneliness, lack of social support and a deterioration of mental health [6]. Subsequent research was able to corroborate this in part [61], though younger age groups were mainly afflicted. During the survey period of Gesundheit 65+, the COVID-19 pandemic containment measures were again intensified from the end of 2021 due to the high risk of infection by the omicron variant of SARS-CoV-2. Against this background, a total of one in five people in Gesundheit 65+ described themselves to be lonely. Loneliness was more pronounced in women than in men, which is consistent with a Japanese study conducted during the same time period [50]. The present results can be compared only to a limited extent to the [results from the German Ageing Survey \(DEAS\) 2020/21](#), which are also presented in this issue of the Journal of Health Monitoring, which is due to methodological reasons: a different instrument was used, persons over 90 years of age were excluded from the study and the data were collected in a telephone interview. With regard to social support, it became clear in Gesundheit 65+ that the majority of participants receive social support, though to a decreasing degree with increasing age, which is consistent with other studies [62]. The effects of social isolation and loneliness on the health of older people are well known

[63, 64], e.g. as a risk factor for dementia [65]. This aspect can be considered further in the future in longitudinal analyses of Gesundheit 65+, e.g. to analyse the correlation between loneliness and morbidity or mental health in more detail. Women were particularly likely to be afflicted by depressive symptoms in Gesundheit 65+; the same applied to men 80 years of age and older or with low education levels.

With regard to health limitations, the results from Gesundheit 65+ show that multimorbidity is a common phenomenon among older people, which is consistent with other studies [66, 67], and that the prevalence varies according to age and gender [68, 69]. People with multimorbidity are more likely to be admitted to hospital, to be prescribed more medication and to have a higher risk of mortality [67, 68, 70]. The bidirectional correlation between multimorbidity and functional limitations that limit activities and participation is well known [71]. These include severe impairments in vision, hearing, cognition, and associated limitations in activities of daily living. In line with other studies, these were reported more frequently with increasing age [72–74]. No gender, age or educational differences were detected for subjective memory impairment. The fact that more than a quarter of the population aged 65+ report memory impairment indicates that there is a need for health care and, if necessary, diagnostics, as subjective memory impairment is considered to be a risk factor for cognition decline, future dementia and mortality [75–78].

Over a quarter of the participants of Gesundheit 65+ report urinary incontinence and the respective proportion increases significantly with age, as has been reported in other studies as well [79–81]. Women are more likely to

report urinary and faecal incontinence than men. As these are shameful issues with serious effects on the quality of life and participation of those afflicted, they should be regularly addressed in medical consultations in accordance with existing guidelines [82] and preventive measures such as pelvic floor training should be offered at an early stage. Incontinence is also associated with frailty [83]. At least one fall event in the past year was common especially among the participants of Gesundheit 65+ aged 80 years and older, with over 30% among men and over 40% among women, a similar prevalence as described by the WHO as early as in 2007 [84]. Falls result in moderate to severe injuries, hospitalisation, fear of falling, loss of independence and premature death [85, 86], which can be prevented or reduced by adequate intervention programmes (personal, medication and environmental measures), but there is still a need to catch up in the implementation of such measures [87].

A comparison of the results with other national ageing studies is only possible to a limited extent due to the different methodological approaches. For example, both the DEAS [88] and the Corona Survey of the Survey of Health, Age and Retirement (SHARE) [89] only collect data from previous panel participants in their 2020/21 wave due to the pandemic. The D80+ study, on the other hand, only surveyed people aged 80 and older with a focus on life situation and quality of life and used other instruments or operationalisations (e.g. for multimorbidity) [90]. For comparison of Gesundheit 65+ and the telephone survey of private households GEDA 2019/2020-EHIS [91], separate further methodological studies are required before a classification of deviating prevalences is possible, e.g. with regard to the prevalence of informal care [92].

### Strengths and limitations

Gesundheit 65+ delivers representative data on the health status and related factors for the older and very old population in Germany. The study included both persons in private households as well as in institutions, without and with severe limitations in health, and proxy participation as well as consent by legal representatives were permitted. The mixed-mode survey design, which allowed for participation via a paper-based, web-based, telephone or face-to-face questionnaire/interview, made it possible for persons to participate who are usually excluded or do not participate in other studies (e.g. persons with severe visual or hearing impairments, support needs or lack of capacity to consent). This is the particular strength of Gesundheit 65+. Due to these measures and the elaborate recruitment process, a good response rate and sample composition could be attained for this age group [93]. For example, there is a good agreement in the proportion of Gesundheit 65+ participants who receive long-term care benefits (17%) compared to 19% among those 65 years of age or older in the general population of Germany according to the data of the Federal Statistical Office [94] (own calculations).

The present study has some limitations as well. The aim of Gesundheit 65+ was to attain a sample that was equally distributed by gender by applying stratified random sampling. However, the proportion of women of 47.9% is lower than that of men. The willingness of invited men to participate was thus higher than that of women, which was balanced out by weighting in the analyses. Further response analyses in Gesundheit 65+ should address this issue in the future, e.g. the inclusion of people in nursing homes and socially disadvantaged neighbourhoods. Gesundheit

65+ will not be able to close the existing data gap especially with regard to the status of older persons in nursing homes, as analyses from the previous studies OMAHA I and the IMOA feasibility study show [95, 96]. Other methodological approaches and monitoring systems are therefore needed for health monitoring in nursing homes [97]. Persons with insufficient knowledge of the German language were excluded from the study, as it was not possible to offer this group adequate participation (e.g. by means of translated questionnaires) in the context of Gesundheit 65+, as was done in other studies by the RKI [98]. In the future, it will be important to expand and link the approaches of Gesundheit 65+ to this population group as well, in order to be able to draw conclusions concerning the health status of all older persons with a migration history, regardless of their knowledge of German.

To minimise the survey participation burden, short survey instruments (e.g. the PHQ-2 instead of the PHQ-8/PHQ-9) or single questions per topic were often used (e.g. on satisfaction with life). The use of instruments or questions that are as simple as possible should enable people with limited reading skills or cognitive function to respond. Accordingly, Gesundheit 65+ allows to paint a broad picture of the health status of older persons in Germany. On the other hand, in-depth statements or analyses on a topic are possible to a limited degree only. For example, on the topic of pain, no information can be given on the location of pain or current treatment. Due to the follow-ups over a period of one year, the home visit examination and the integration of external data sources, Gesundheit 65+ will in future offer a wide range of options for analysis of the health status and resources and risk factors of those aged 65 and

older in Germany. This also applies to other relevant concepts of healthy ageing that could not be adequately represented by the baseline survey. For example, only in the future it will be possible to analyse the age-relevant concept of frailty [99] with additional measurement data from the home visit examination, e.g. on hand grip strength and cognitive function.

### Outlook

Gesundheit 65+ presents a comprehensive database for description of the health status of old and very old people in Germany. It comprises a) survey data from four waves over the course of one year, b) examination data parallel to the last health questionnaire/interview and c) linkage to external data sources [see also 13]. The latter includes data from the statutory health insurance funds, an all-cause mortality follow-up over 20 years via the residents' registration offices (i.e. a query on vital status and, if applicable, the notification of the date of death) and data describing the living environment via geographic information systems [100].

In the future, this database can be used, for example, to describe longitudinal associations between physical and cognitive functioning, depressive symptoms and mortality risks. The objective measures of the examination can be used to assess the consistency with self-reports (e.g. on subjective memory impairment or on height and weight) in future analyses. Gesundheit 65+ contributes to the description of resources and risk factors related to the health status of older and very old. Based on this, recommendations for action for policy and practice can be derived.

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### Data protection and ethics

Gesundheit 65+ was conducted in strict compliance with the data protection regulations of the EU Data Protection Regulation (DSGVO) and the Federal Data Protection Act (BDSG). Before commencement of the study, the implementation of the study was approved both by the official data protection officer of the Robert Koch Institute and by the Ethics Committee of the Berlin Medical Association (Eth-50/19). Participation in the study was voluntary and could also be declined in parts. For participation in Gesundheit 65+, either the invited person or her/his legal representative gave written consent. In the context of an online baseline survey, the invited person could also give consent online.

### Data availability

The authors state that some access restrictions apply to the data on which the results are based. The data set cannot

be made publicly available because the informed consent of the study participants does not cover making the data publicly available. The data set underlying the results is archived at the Research Data Centre of the Robert Koch Institute and can be accessed by researchers upon reasonable request. The data can be accessed on site in the Secure Data Centre of the Research Data Centre of the Robert Koch Institute. Enquiries can be made by e-mail to [fdz@rki.de](mailto:fdz@rki.de).

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### Conflicts of interest

The authors declare that there is no conflict of interest.

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# Dementia in Germany: epidemiology, trends and challenges

## Abstract

**Background:** Dementia poses a growing challenge for individuals, healthcare, social support, and society amidst the ongoing ageing of populations. To evaluate the care requirements and social implications of dementia in Germany, reliable statistics regarding its current and future occurrence are necessary.

**Methods:** Using existing data sources and recent research results, this paper compiles and analyses relevant statistics on the occurrence of dementia in Germany, presents protective and risk factors, and options for care provision.

**Results:** Recent projections indicate a potential surge in the number of dementia patients in Germany, predicted to rise from 1.7 million at present to up to 3.0 million by the year 2070. Cognitive and motor deterioration and behavioural changes associated with dementia lower the ability to live independently. These changes are often tied to social exclusion and stigma and, particularly in the severe phase of the disease, necessitate extensive medical and care requirements. This contributes to dementia being one of the most costly diseases at old age from an overall societal perspective. Currently, there are no curative treatment options available.

**Conclusions:** To reduce the increase in the number of dementia patients and associated costs in the future, preventive approaches, particularly promoting a healthy lifestyle, may prove effective. Simultaneously, the healthcare system, society, and caregivers must prepare for the increasing number of dementia patients. Improved diagnostics, new forms of therapy, and social innovations that support those who are affected and their relatives can help reduce the burden of dementia and its associated costs.

POPULATION AGEING · HEALTH TRENDS · DEMENTIA · NEED FOR CARE · DEMENTIA PREVENTION · BURDEN OF DISEASE

## 1. Introduction

Germany's demographic development is characterized by declining birth rates and increasing life expectancy. Over the past 30 years, life expectancy at the age of 65 has increased by 3.1 years for women (from 18.0 to 21.1 years) and by 3.5 years for men (from 14.3 to 17.8 years) [1]. Consequently, more and more people – predominantly women – are reaching very high age; for example, the number of people aged 85 and older rose from 1.1 million

in 1990 to 2.5 million in 2020, and is expected to at least double by 2070 [2]. The rising number and proportion of elderly people in the population is associated not only with an imbalance between the working and care-dependent population, but also with health-related challenges. Advanced age is one of the most important health risks [3], and dementia is one of the most common age-associated diseases. In 2019, about 1.7 million people with dementia lived in Germany [4] and forecasts indicate a future increase in their number up to 3.0 million by 2070.

## Infobox 1 Dementia

Dementia is not a part of normal aging, nor is it a disease in and of itself. Instead, it is a collection of symptoms with diverse causes, signs, severity levels, and courses of disease. It is essentially characterised by changes in the brain and is associated with memory loss and changes in one's personality [5, 6].

Based on the underlying disease, a distinction can be made between primary and secondary dementia (Figure 1).

A total of 90% of the dementia cases are primary dementia, which originate directly in the brain and are incurable. These include neurodegenerative forms, such as Alzheimer's dementia, Parkinson's disease dementia, Lewy body dementia or frontotemporal dementia. Non-neurodegenerative forms include vascular dementia, infectious dementia, such as sporadic Creutzfeldt-Jakob disease, or hereditary forms of dementia.

A total of 10% of dementia cases are secondary dementia (secondary to other underlying diseases), and can, in principle, be cured [7]. Metabolic, nutritional or poisoning-related diseases (e.g. vitamin E deficiency, alcohol and drug consumption), bacterial or viral infections (e.g. HIV) or head injuries can cause them [7–9].

**Figure 1**

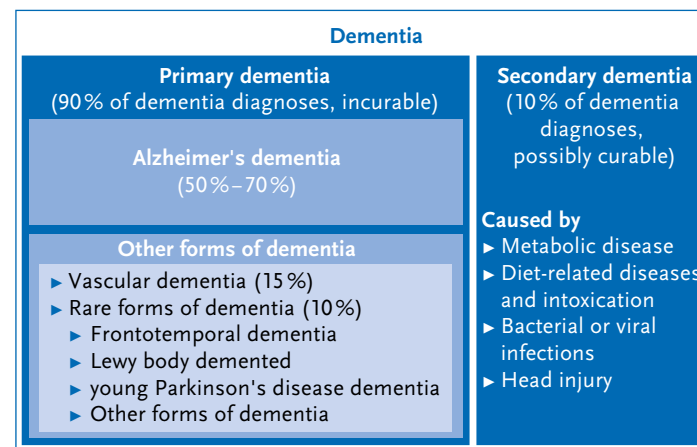
### Forms of dementia

Source: Figure based on [7–11]

Against this background, the article presents a clinical overview of dementia, as well as its epidemiology, risk factors, preventive measures, and care requirements.

## 1.1 Forms of dementia

Alzheimer's dementia (50%–70%) and vascular dementia (15%) are the most common forms. Rare forms of dementia, such as frontotemporal dementia, Lewy body dementia or dementia caused by a previous disease (e.g. Parkinson's disease), comprise approximately 10% of the cases [10, 11]. It is difficult to exactly determine the proportions of the various forms of dementia due to their varied origins and symptoms as well as the inconsistency of their diagnosis. Autopsy studies suggest that at the end of their lives, most people suffering from dementia have a combination of Alzheimer's dementia and vascular dementia [12].



Normal cognitive ageing processes and mild cognitive impairment are not discussed in this article, although they are often considered to be precursors of dementia [13]. The focus is on senile dementia, which has its onset approximately at the age of 65 [11].

## 1.2 Course and symptoms

Most forms of dementia have a gradual onset. As a result, distinguishing between general cognitive ageing and early mild dementia is challenging. Defining the transition from normal cognitive ageing to the early stages of cognitive disease is difficult [13]. While individuals with normal cognitive ageing can compensate for the cognitive losses and can act independently [14], dementia is characterised by a more rapid, progressive decline in cognitive performance. This is apparent in areas such as orientation, communication skills, attention, and concentration [29, 30]. Moreover, almost all forms of dementia are accompanied by varying psychological well-being and behavioural changes, including depressive symptoms, anxiety, sleep disorders, delusions or aggression [9]. Depending on the specific form of dementia, other symptoms, such as speech disorders, mood swings, motor impairments or hallucinations may occur as well. The broad range of symptoms makes it difficult to accurately diagnose dementia and determine its severity. In addition, distinguishing the core psychological symptoms of dementia from those of other underlying diseases is difficult [9].

## 2. Methods

### 2.1 Data and data collection

It is common to use either population-based epidemiological surveys or health claims data from statutory health insurance companies to analyse dementia. Standardized neuropsychological tests are commonly used in epidemiological surveys to measure cognitive impairment and investigate the causes of diseases [15, 16]. The scientific use of these surveys has limitations due to their low case numbers, particularly when considering subgroups (e.g. by age, gender). There are also representativeness issues due to sample recruitment or different diagnostic procedures by physicians. Additionally, people who are in poor health and residents of care institutions are often excluded [17].

Health claims data are produced during the standard delivery of healthcare and nursing care. Physicians generate these data while billing their medical services to the healthcare insurer. Although health claims data are collected without any scientific intent, they permit tracking the complete disease and healthcare utilisation of a large number of individuals over time. This includes individuals residing in private households and nursing homes [18]. Diseases are usually recorded using the ICD-10 classification system. However, health claims often do not comprise clinical information and external validation of diagnoses is not possible. Furthermore, they are subject to legal changes.

The epidemiological measures of dementia in this article are based on anonymised claims data from the Allgemeine Ortskrankenkassen (AOKs), the largest statutory health insurance provider in Germany. This data covers

approximately one third of the total population, which is equivalent to 26.8 million insured individuals. The AOK data includes payments made to certified physicians for outpatient care (according to §295 para. 2 SGB V) and inpatient care (according to §301 para. 1 SGB V). The following ICD-10 codes were used to register cases of dementia: G30, G31.0, G31.82, G23.1, F00, F01, F02, F03 and F05.1. This article does not distinguish between different types of dementia, as a significant proportion of diagnoses were for non-specific dementia (F03). Previous studies have indicated that AOK data is appropriate for estimating the prevalence, incidence, and trends in dementia over time [19].

### 2.2 Estimation of incidence and prevalence

Prevalence and incidence are the most important epidemiological measures for describing the extent of a disease. Prevalence refers to the proportion of current cases of a disease in a total population during a specific period of time. Incidence is the rate of new cases of a disease among the healthy population who are at risk of acquiring the disease within a specific timeframe [20]. The current prevalence estimates are based on a 2.2% random sample of individuals aged 50 years and over, insured by AOK in the year 2014. Incidence estimates were produced by following individuals from the base year until 2019.

### 2.3 Forecasting the number of dementia patients

Forecasting models for predicting the future number of dementia patients take into account changes in population structure, life expectancy and the prevalence of dementia.



Based on age-specific dementia prevalence (see [3.1 Prevalence and incidence](#)) and the 15th Coordinated Population Projection of the Federal Statistical Office (variants: G2L2W2 – moderate increase in life expectancy, G2L3W2 – large increase in life expectancy [21]), we projected the number of dementia patients aged 65 and older in Germany until 2070. To achieve this, we used the moderate migration scenario for the population projections (W2) and two different scenarios for the development of dementia prevalence: The status quo scenario (S1.1 and S1.2) assumes a constant disease prevalence with increasing life expectancy, while the prevention scenario (S2.1 and S2.2) assumes a reduction in age-specific disease prevalences by 1 % per year.

## 2.4 Disease burden of dementia

The impact of dementia on population health was calculated using data from the BURDEN 2020 project at the Robert Koch Institute (RKI). To represent the burden of disease, the disability-adjusted life years (DALY) indicator was used. This indicator combines the years of life lost due to death (YLL, years of life lost, known as the mortality component) and the years lost due to health impairment (YLD, years lost due to disability, morbidity component) within the population [22]. YLL represent the gap between the disease-related age at death and the age-specific remaining life expectancy. YLD is derived by combining the disease prevalence with the disability weight, which indicates the degree of impairment. Consequently, one DALY equals one year of healthy life ‘lost’.

The AOK data were also used to calculate the YLD related to dementia in this article [22]. The cause of death statistics were used to calculate the YLL [22, 23]. The cause of death statistics show the basic illness (underlying cause of death) for each deceased person. However, there are also direct (the last illness that was directly fatal) and contributing causes of death [24]. Diseases such as heart attack or lung cancer are more directly associated with death than dementia. Therefore, these diseases are recorded more accurately as the underlying cause of death. In contrast, dementia is often regarded as a contributing cause of death, which means that dementia is not fully recorded in the cause of death statistics [25]. This, in turn, may result in an underestimation of the overall burden of disease caused by dementia.

## 3. Epidemiology of dementia

### 3.1 Prevalence and incidence

In 2014, the prevalence of dementia at age 65 and older was 10.3 % in Germany, and was 1.7 % in the group of 65 to 69 years of age. It rises exponentially with increasing age, doubling roughly every five to six years until the age of 80 to 84. From age 95, the prevalence stabilises at a high level ([Table 1](#)).

From 2014 to 2019, the incidence of dementia at age 65 and older was 2.4 new cases per 100 person-years. The incidence is characterised by an exponential increase with age ([Table 1](#)). In the age group of 65 to 69 years of age, there were 0.4 new diagnoses per 100 person-years in men and women combined. This number increases with age, up to 11.3 (men) and 11.9 (women) in the group of 95 years

Table 1

Age-specific prevalence of dementia per 100 persons in 2014 and age-specific incidence of dementia per 100 person-years in 2014–2019 (from age 65), Germany (n=83,504 women, n=55,958 men)

Source: Sample from health claims data of all persons insured with AOK 2014–2019

Age group	Prevalence			Incidence		
	Women	Men	Total	Women	Men	Total
65–69 years	1.6	1.9	1.7	0.4	0.4	0.4
70–74 years	3.7	4.1	3.9	1.0	1.1	1.1
75–79 years	7.4	7.9	7.6	2.0	2.3	2.2
80–84 years	15.6	14.5	15.2	3.9	3.6	3.8
85–89 years	25.0	21.2	23.9	6.2	6.2	6.2
90–94 years	36.5	28.9	35.0	9.5	9.0	9.4
≥95 years	43.5	33.7	42.1	11.9	11.3	11.8
<b>Total</b>	<b>11.8</b>	<b>8.2</b>	<b>10.3</b>	<b>2.7</b>	<b>2.1</b>	<b>2.4</b>

## Population ageing contributes to an ongoing increase in the number of dementia patients.

Figure 2

Forecast of the number of dementia patients aged 65 and older in Germany by 2070 (n=83,504 women, n=55,958 men)

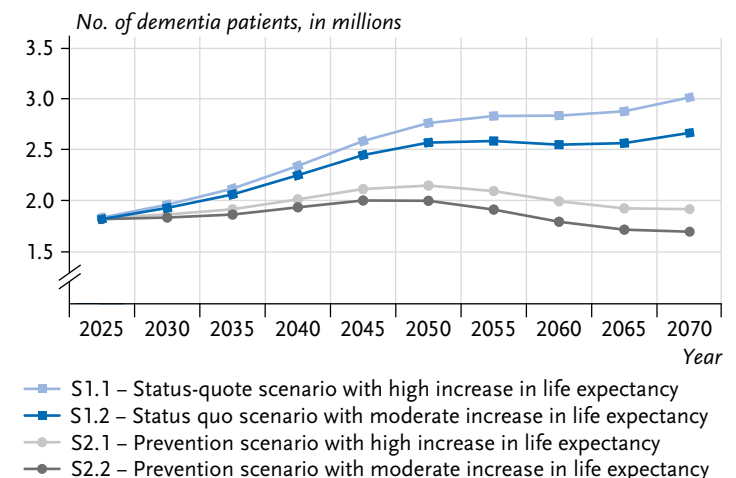
Source: Sample from health claims data of persons insured with AOK 2014–2019 and 15th Coordinated Population Projection of the Federal Statistical Office [21]

and older. Gender differences in the prevalence can be explained by higher mortality rates among men, which leave only the healthiest individuals to survive into old age.

### 3.2 Forecasts

Previous forecasts up to 2060 indicate that there will be a decline in the number of dementia patients from around 2050, when the large baby boomer cohorts (born in the 1950s and early 1960s) will be 85 years of age or older [4]. Even when taking into account the increase in life expectancy, at this high age mortality is high and remaining life expectancy low [26], so that the contribution of this large cohort to the total prevalence at age 65 and older will get progressively smaller over time [26]. In the present status quo scenario, the number of dementia patients aged 65 and older will increase from an estimated 1.8 million in 2025 to 2.8 million (scenario S1.1) or 2.6 million (scenario S1.2) in 2055 (Figure 2). Thereafter, there will be a further sharp increase when, from 2055 onwards, the children of the baby boomers (born between 1980 and 1995) enter the age groups with high prevalence of dementia. By 2070, the

number of dementia patients will increase to 3.0 million (S1.1) or 2.7 million (S1.2). If the prevalence of dementia can be reduced by an average of 1% per year, the number of dementia patients would increase to a maximum of 2.2 million (S2.1) or 2.0 million (S2.2) in 2050. Subsequently, the number would drop again to 1.9 million (S2.1) or 1.7 million (S2.2) persons in 2070. Despite inherent uncertainty and various influencing factors, such as migration, pandemics, and changes in mortality patterns, projections for 2070 suggest that the number of dementia patients will still increase after the baby-boom generation has passed unless preventive measures are implemented or new therapies are developed.



**Cognitive, motor, and psychosocial symptoms associated with dementia reduce the quality of life and impair the ability to live autonomously.**

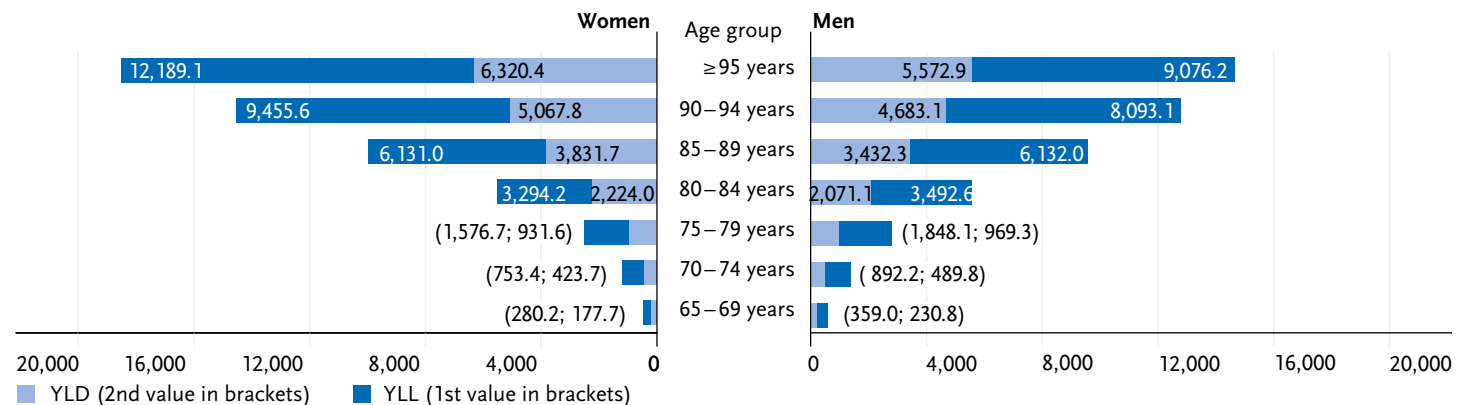
### 3.3 Mortality

Dementia patients have higher death rates and a shorter life expectancy than those who are not afflicted by dementia. In a Swedish study, the average survival time of dementia patients is 4.8 years in the age group of 75 to 84 years of age and 3.8 years in the age group of 85 years and older [27].

The progressive health decline during the course of disease increases the risk of falling, multimorbidity and infections. Pneumonia, urinary tract infections, bone fractures or organ failure, for example, occur more frequently in persons with dementia, which increases their mortality risk. As a result, in the period from 2014 to 2017, dementia was the most common disease at the time of death among women aged 70 years or older and the fifth most common disease among men. In 2060, dementia will maintain this position among women and become the second most common disease at the time of death among men, as illustrated by a study for Germany based on AOK claims data for the years 2014 to 2017 [28].

### 3.4 Burden of disease

The burden of disease increases sharply with age for both women and men. On average, 100,000 men 65 to 69 years of age lost 590 years of life due to dementia (health impairment and death, DALY), compared to 458 years in women of the same age. At age 95, the number of years lost to dementia (DALY) increases to 18,509 years per 100,000 women and 14,649 years per 100,000 men (Figure 3). It is also evident – despite the potential under-reporting of dementia as a cause of death, as only the underlying cause of death is taken into account for the calculation (see Chapter 2.4) – that a larger share of the burden of disease is attributable to deaths due to dementia (YLL). The proportion due to dementia-related disability (YLD) is lower for all age groups. Deaths account for almost two-thirds of the disease burden in individuals aged 65 and older (women: 62.3%, men: 63.8%), while health impairment measures approximately one-third (women: 37.7%, men: 36.2%).



**Figure 3**

**Burden of disease (DALY per 100,000 persons by YLL and YLD) of dementia with increasing age and by gender in 2017**

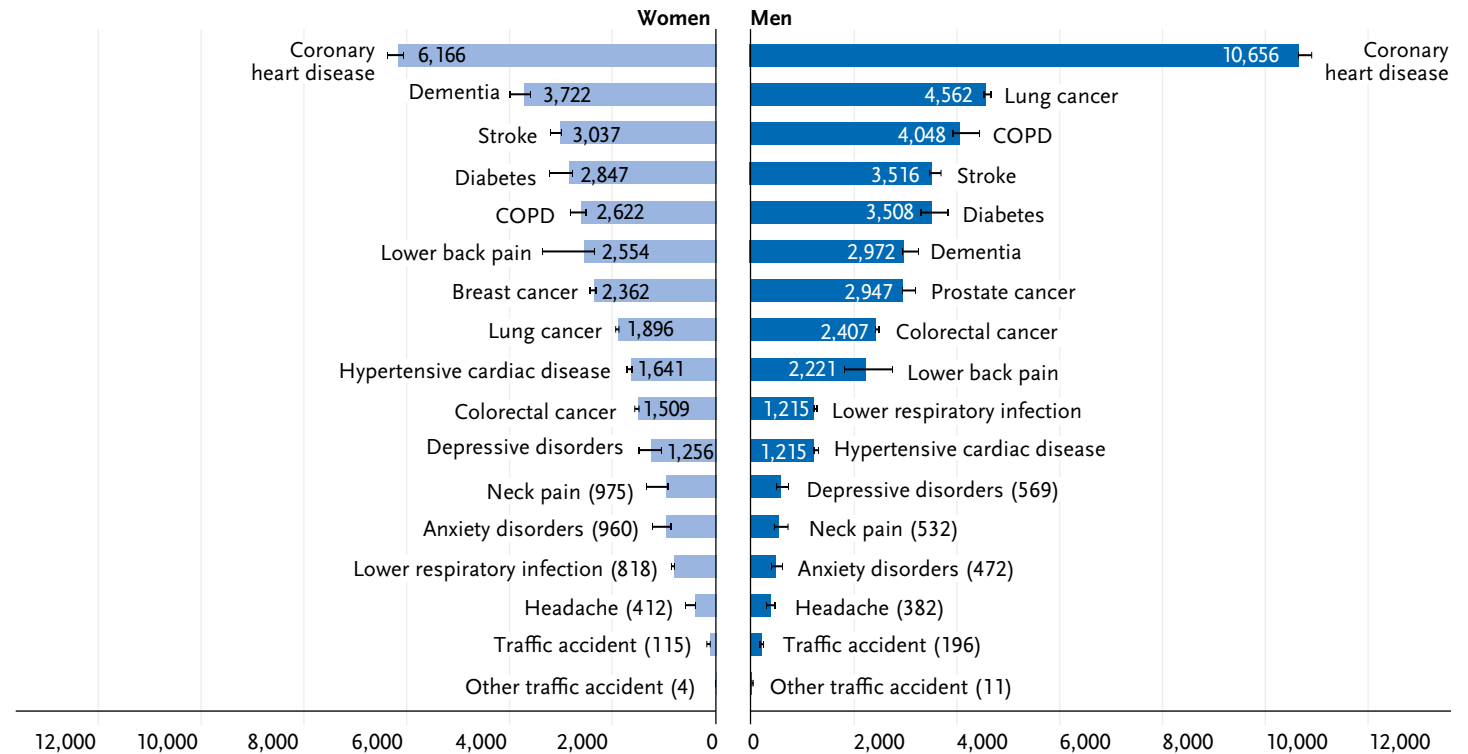
Source: Robert Koch Institute, special analysis of the BURDEN 2020 study

Figure 4

### Total burden of disease (DALY per 100,000 persons) for the most common causes of burden of disease by gender at age 65+

Source: Robert Koch Institute, special analysis of the BURDEN 2020 study (ranking based on selected important causes of burden of disease, see [22])

**Dementia is linked to substantial costs to society because of the considerable requirement for care.**



In 2017, the dementia-related burden of disease in the group of 65 years of age and older was 3,722 DALY per 100,000 persons for women and 2,972 DALY per 100,000 persons for men (Figure 4). When comparing the burden of disease for different illnesses, coronary heart disease resulted in the highest number of years of life lost for both women (6,166 DALY) and men (10,656 DALY). Dementia ranked second for women (3,722 DALYs) and sixth for men (2,972 DALYs) among the major causes of burden of disease selected herein (Figure 4).

### 3.5 Costs

Due to the high need for care and the high multi-morbidity, dementia is one of the most expensive group of diseases from the age of 65. The direct medical and non-medical costs of illness borne by the health and care insurance companies make up only a small fraction of the total costs. Of greater importance are the indirect costs for nursing and care: A total of 75% to 80% of the illness costs of dementia are accounted for by lost income and tax losses due to informal care [17, 29]. Informal care is usually provided without payment by family care givers, friends,

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## Lifestyle factors play a critical role in determining the risk of dementia and may offer strategies for prevention.

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neighbours or other non-trained care givers in the domestic environment of the person in need of care [29]. It is an important cost factor especially when care givers reduce or terminate their employment to be able to provide care [30].

Because the costs associated with dementia occur in a variety of settings and are not fully captured, such as lost income for caregivers, they must be estimated. These estimates are based on assumptions and therefore vary to some extent. According to a comprehensive meta-analysis, the direct annual cost of dementia for people aged 65 and older in 2016 was approximately €34 billion for health and care insurance companies, including expenditures on, prevention, treatment, and rehabilitation, and an additional €73 billion in costs to society as a whole, mainly due to informal care. The costs of informal care only consider services that result in a loss of productivity, for example when employed persons reduce their working hours to provide care. It is expected that these costs will rise to €90 billion (direct costs) and €195 billion (indirect costs) by 2060. The average annual direct cost per dementia patient is about €20,658 for the health insurance and €44,659 for society as a whole. Compared to individuals without dementia, the yearly excess costs per person are €11,205 for the health insurance and €33,188 for the society as a whole [31].

### 4. Risk factors and prevention

#### 4.1 Risk factors

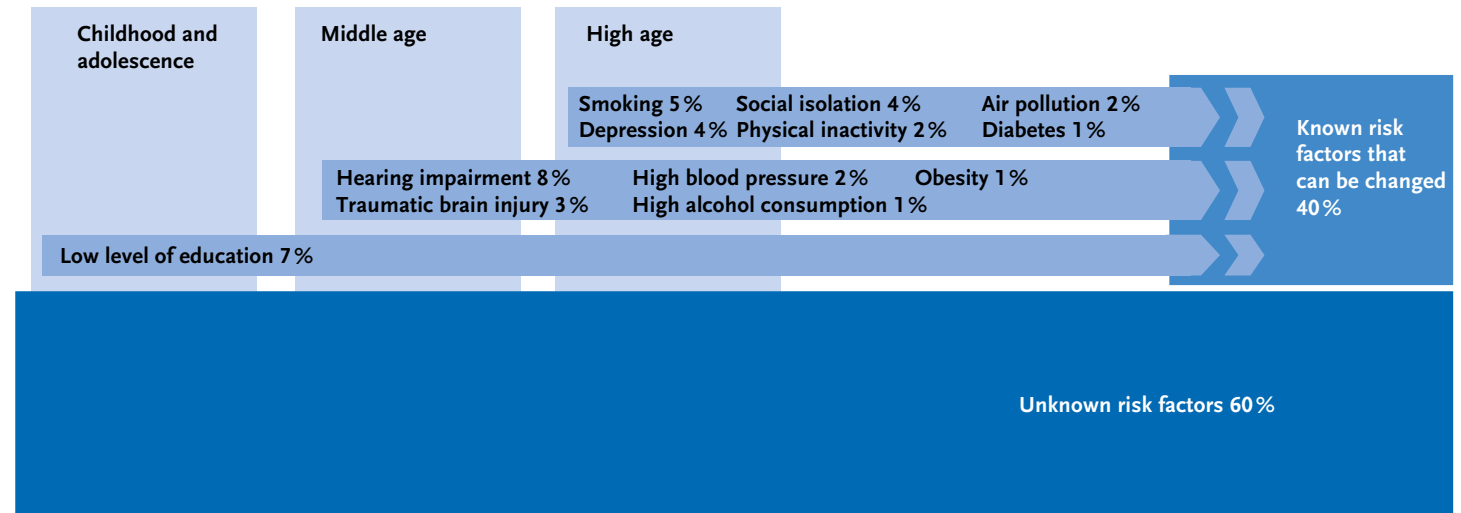
Dementia develops over the course of decades and sometimes manifests long before symptoms become apparent. The diverse forms of dementia also contribute to the fact

that around 60% of dementia cases are still unexplained in terms of their causes, as indicated by the *Lancet Commission on dementia prevention, intervention, and care*. This implies that a substantial portion of the factors that increase the risk of dementia is still unknown [32]. Around 40% of the dementia cases are therefore attributable to risk factors over the entire life course and could thus be prevented (Figure 5). An international meta-analysis identified 26 risk factors for dementia [33]. Notably, the risk factors identified for Europe largely overlap with those highlighted by the Lancet Commission. Apart from age and gender, social, lifestyle and health-related factors, e.g. other diseases, are important dementia risk factors [32]. They collectively contribute to the risk of dementia and provide crucial foundations for preventive measures.

Educational level is an important predictor of overall health and dementia, with individuals with high education having a lower risk of dementia. This association has been attributed to two indirect pathways: better educated individuals often have healthier lifestyles and education increases cognitive reserve capacity, which allows for compensation of the cognitive decline [34, 35].

In middle age (45–65 years), hearing loss has the greatest impact of all identified risk factors: Approximately 8% of dementia cases could be prevented [32]. Presumably, secondary effects, such as depression or social isolation, may explain this association, at least in part [36]. The *Lancet Commission on dementia prevention, intervention, and care* also identified traumatic brain injury, hypertension, heavy alcohol consumption and obesity as relevant factors in midlife [32]. Studies in Germany corroborate all these risk factors [37–39].

**Figure 5**  
**Risk factors of dementia; percentages illustrate the possible decrease in dementia prevalence if the corresponding risk factor were eliminated**  
 Source: own presentation according to [32]



**Society, healthcare, medicine, and politics must develop viable solutions to address the increase in the number of dementia patients, including finding suitable care options.**

At advanced age, about 5% of the dementia cases are due to tobacco use [32], while another 4% each are due to depression and social isolation. Physical inactivity, which is closely linked to risk factors mentioned above, explains another 2% of all dementia cases. Even some limitations in mobility, for example disturbances of the gait pattern [40] or injuries to the lower extremities [41], might be associated with an increased risk of dementia. Diabetes accounts for 1% of all dementia cases, with numerous studies showing the significance of this metabolic disease in the onset of dementia [39, 42, 43]. Environmental factors, measured as air pollution, have also been demonstrated to affect cognitive performance [44]. Structural characteristics such as regional differences in wealth can also contribute to differences in the risk of dementia [35]. One study for Germany shows that about 30% of Alzheimer's dementia cases were attributed to

seven risk factors, namely diabetes, high blood pressure and obesity in middle age, depression, physical inactivity, smoking and low educational level [45].

Other studies showed that cardiovascular diseases such as strokes and coronary heart disease, as well as elevated blood cholesterol levels (hypercholesterolaemia) [39, 46, 47] may increase the risk of dementia. Also drug therapies used for other diseases, for instance, antipsychotics, urological drugs, or psychostimulants [37] are linked to a higher risk of dementia. On the other hand, some drugs may even have a protective effect and might be associated with a lower risk of dementia [48]. According to recent research, another factor that could influence cognitive health might be the interaction between the central nervous system and the gut microbiome, although the underlying mechanisms are not yet fully understood [49].

It should be borne in mind that many of the effects may be indirect as well as direct, and that risk factors may interact. In particular, the presence of multiple risk factors adversely affects the risk of dementia [50].

#### 4.2 Prevention

Effective dementia prevention thus requires above all the reduction of lifestyle-related impairments and pre-existing conditions [51]. A healthy lifestyle, including a balanced diet, a healthy body weight, avoiding alcohol and smoking, can achieve this. Promoting physical activity is especially important in this context because it accounts for about two out of ten Alzheimer's dementia cases in Germany, making it one of the most influential factors in reducing the risk of dementia [45]. Furthermore, reducing and diagnosing dementia-related illnesses, such as hearing loss, depression, high blood pressure, and diabetes, early and treating them appropriately can help prevent dementia. It should be noted that some studies presume complete elimination of risk factors [32] or a strong decrease in risk factor prevalence [45]. Thus the actual prevention potential might be overestimated. Using the example of type 2 diabetes in the age group of 75 and older, a study based on AOK data from 2014 shows that a 1% reduction in this disease alone could reduce the number of dementia cases by about 30,000 in 2040. If the incidence of dementia among diabetics was successfully reduced by just 1%, 220,000 dementia diagnoses could be prevented [43]. International studies highlight that promoting stimulating cognitive, physical, and social activities could potentially have a strong prevention impact [52, 53].

At the societal level, social inclusion, reducing environmental stress and regional economic inequality, as well as increasing educational attainment have shown promise in the prevention of dementia. The latter also includes formal education as well as maintaining cognitive performance in old age, e.g. through lifelong learning or memory training. Combining multiple protective factors and reducing risk factors over the course of life simultaneously has a particularly beneficial effect [54]. Almost all protective factors have in common that they can reduce both the risk of dementia and the risk of severe disease progression [47]. Since even mild cognitive impairment can be associated with an increased risk of dementia [55], early diagnosis and treatment of dementia is also proving to be an important element in the delay of the severity progression of the disease [56, 57].

### 5. Care

#### 5.1 Care options

While the development of new antibody therapies is raising cautious hope for a therapy for dementia [58, 59], at this time there are no drugs that can effectively prevent or slow down the disease. Therefore, the focus is on measures for long-term care as well as for improving the quality of life, for maintaining social, cognitive and everyday abilities and for delaying the progression of the disease. In the mild stage of the disease, non-drug therapies such as cognitive training, occupational and physiotherapy and psychosocial interventions can promote well-being and maintenance of function. This is one of the reasons why a number of innovative life management services for people with dementia have been developed in recent years.

**Infobox 2****National dementia strategy**

The recommendations for action for the global handling of dementia contained in the *Global action plan on the public health response to dementia 2017–2025* of the WHO have been taken into account for Germany in the National Dementia Strategy ([www.nationale-demenzstrategie.de](http://www.nationale-demenzstrategie.de)). The strategy comprises a total of 162 measures and 27 sub-goals in four fields of action:

- ▶ Developing and establishing structures for social participation of people with dementia at their place of residence
- ▶ Providing support to people with dementia and their relatives
- ▶ Advancing medical and nursing care for people with dementia
- ▶ Promoting excellent research on dementia

The 162 measures of the National Dementia Strategy are designed to contribute to improving the living situation, everyday life, social participation and healthcare and nursing care given to dementia patients and their relatives. This includes, for example, new social spaces and mobility concepts, raising public awareness, new housing concepts, (expanded) counselling services for dementia patients and their relatives, strengthening and improving care, and in-depth dementia research [68].

**5.2 Provision of care**

A total of 90% of dementia patients require end-of-life care due to the loss of function caused by the disease. Therefore, dementia is one of the main reasons for requiring care [29]. Coping with the need for care is predominantly a private and familial matter: the majority of the dementia patients live at home, and about two thirds of them receive informal care from close relatives [31, 60].

This form of care applies mainly to younger dementia patients or those in an early, mild stage of the disease. Most dementia patients prefer family care [61] and it is an essential pillar of the provision of care in Germany. However, informal care is also associated with high societal costs and health, mental and financial burdens for the care givers, typically spouses, children or other family members. Women bear a significantly higher burden of care [29, 31, 62, 63].

People with dementia require care for longer periods and have higher demands and burdens than those without dementia due to core and psychosocial symptoms [64]. Professional outpatient or inpatient care is usually only sought when the disease becomes more severe [65]. There is already an imbalance between the demand for and supply of care, which is expected to increase in the future. According to forecasts, the number of people with statutory health insurance who are in need of long-term care will increase from about 3.3 million in 2017 to about 5.1 million in 2060 [66], and the number of the recipients of informal care increasing from 3.1 million to 4.1 million [67]. Professional outpatient care is expected to increase from 0.9 to up to 1.4 million persons in need of care, and insti-

tutional care is expected to increase from 0.8 to up to 1.3 million persons [67]. These figures will peak in 2050, but could be significantly reduced by improvements in morbidity, mortality and risk factor development. To meet the growing demand for care, the number of professional care workers in the outpatient and inpatient sectors would need to increase by about 394,000 persons (from 586,000 in 2017 to 980,000 in 2060) [66]. However, the increasing demand for care is offset by a decline in the available care workers of about 20%, and the informal care potential in the population, i.e. the number of potential informal care givers, is also expected to increase less strongly than the demand for care [67].

**5.3 Recent programmes and offers for care and support**

Various services that are sensitive and responsive to the needs of individuals with dementia and that complement therapy and nursing care have been developed recently. These services can enhance the well-being of dementia patients by preserving their participation and autonomy. They are often regional or temporary social structures and have a significant impact on the everyday life, e.g. dementia gardens, animal-assisted interventions, musical and artistic activities or sports groups [69]. Digital or technical aids, on the one hand in the form of online self-help groups or dementia podcasts, on the other hand as support in home care, e.g. in the form of tracking devices or security measures such as cooker detectors or key finders, can promote the exchange between those afflicted as well as their integration into the non-afflicted society. Such measures can also delay the need for institutional care [69, 70].



Residential projects also enable people with severe illness to live together independently, within a secure environment outside of inpatient or nursing homes. Residential groups, including those tailored to specific groups such as dementia patients with a migration history or homosexual dementia patients, promote social interaction and have been linked with enhanced quality of life and cost efficiency [71].

Local dementia networks are a cooperation of interdisciplinary medical, nursing and social services that provide a networked spectrum ranging from counselling and diagnostics to therapeutic support. As such, they partly enable holistic care and create an interface for dementia patients receiving outpatient care, their relatives and other actors [72]. Studies show the effectiveness of these networks, e.g. with regard to better pharmacological and medical care [73].

## 6. Conclusion and outlook

Dementia is a significant health issue in Germany and poses a major challenge not only for individuals, but also for society, nursing care and medical care. This challenge is expected to continue to grow in the upcoming decades due to demographic ageing, also depending on medical and health developments. Short-term migratory movements may affect the number of future dementia patients, even though large migratory flows are less frequent in older age groups. Since there is no cure for dementia at this time, even good prevention could at best compensate for the effects of the progressive ageing of society on the occurrence of dementia. Consequently, the health and care system, as well as society, should develop solutions that meet the needs of the increasing number of dementia patients.

Efficient and comprehensive dementia diagnosis, treatment, care and support are crucial for mitigating the impact of dementia on individuals and the society as a whole [51]. Medical care for dementia patients is based on four pillars affecting the disease's progression and impact: early diagnosis, thorough symptom and impairment assessment, precise staging and monitoring, and tailoring of therapies [47]. Diagnosis, also with a view to the severity of the disease, is often inaccurate due to the broad and unspecific clinical symptoms [47] – which means that treatment options cannot be fully exploited. Dementia patients usually receive comprehensive medical care from neurologists and general practitioners, but diagnostic work-ups in the early stages of the disease and interdisciplinary treatment have so far been subject to limitations [30, 74]. Approaches for further development are therefore evident in integrated care and in improving basic knowledge about dementia that is conveyed in medical and nursing training [75]. However, this requires a higher utilisation by those afflicted at an early stage, when early and unspecific symptoms become manifest [57].

Due to the reduced informal and formal care potential and the increasing demand for care, changes in the care sector are still necessary. Informal care givers need support [51], as legal, social, emotional and financial services can alleviate the burdens of care giving. Telemonitoring and telemedicine are appropriate for improving the medical monitoring and effectively assessing the progress of disease, even in a home environment. With regard to institutional care, alternative care settings, such as innovative forms of housing or technical aids, have been shown to improve the conditions for both care givers and dementia patients [69, 70].

However, dementia is not solely a medical problem, but also a societal concern. This relates to the growing demand for informal care as well as the public visibility of dementia patients and their social integration. The stigmata and fears associated with the disease among the population and those afflicted contribute to social exclusion [76]. What seems desirable in this regard is greater acceptance of and sensitivity for the disease and a broader general understanding of dementia in society [51], as well as early education about the course of the disease and possible encountering strategies between those who are afflicted and those who are not. This could reduce uncertainties and ambiguities experienced by patients and their relatives, especially at the onset of the disease [68]. In the further course of disease, a dementia-sensitive environment is needed, that not only recognizes the behavioural changes and communicative, motoric-cognitive impairments associated with the disease, but also provides a supportive and safe environment [68, 69]. Both factors could help maintain the autonomy and quality of life, and thus also reduce the progression of disease and dependency on care. Civil society initiatives can help address these needs and may serve as an essential supplementary approach [69]. Studies have shown the efficacy of such innovations for dementia patients [70, 71]. However, certain groups, such as dementia patients in structurally weak areas, those with a migration history, or in an advanced stage of the disease, may not be adequately reached by these services [69]. Therefore, it is important to establish existing services throughout Germany and in a structured manner, and to promote new services for specific target groups [68, 69].

At the societal and individual level, there is still a need to raise awareness of the risk factors of dementia. Living a healthy lifestyle has potential to decrease not only the risk of dementia but also the likelihood of other illnesses [77]. It is essential to not only consciously evaluate one's lifestyle but also minimize health disparities [77]. By adopting preventive measures, the healthcare system could reduce the cost of treatment and care relating to dementia while providing benefits.

Although dementia and the afflicted individuals have become more present in society in recent years, the public remains unaware of the available services and strategies. The National Dementia Strategy, which considers the various actors and provides a framework for action, is a comprehensive set of measures that was introduced for the first time in Germany. The promotion of in-depth dementia research within the National Dementia Strategy, for example through measures for basic and epidemiological research, can provide important new insights into the various forms of dementia, their risk factors and their impact [68]. However, representative data are currently lacking to adequately represent the diversity of the populations. Minorities, such as ethnic or gendered minorities are only rarely taken into consideration [78]. The health claims data used herein are also subject to bias. For example, those insured by the AOK have a lower socioeconomic status and a higher morbidity rate on average compared to others with statutory or private insurance [79]. Furthermore, the health claims data are primarily compiled for billing purposes, rather than for epidemiological analyses. The documented diagnoses thus only partially reflect the epidemiological disease development at the population level, because they

only record persons who have consulted a doctor and had a diagnosis made. On the one hand, coding errors and false-positive diagnoses can occur, on the other hand, cases of dementia in their early stages are sometimes not diagnosed at all [28, 43]. To plan effectively, gain better insights into dementia's development, identify options for action, and provide efficient care to dementia patients collecting more clinical, epidemiological, and population-based routine and survey data is necessary for the future. Considering recent research directions, additional information, such as biomarkers, should be included [78]. From the point of view of research and in the interest of patients, greater transparency and availability of already existing data sources as well as the integration of new data sources, for example information from electronic patient records, are desirable and urgently needed.

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#### Data protection and ethics

Access to the health claims data was granted and approved by the Scientific Institute of the AOK (WIdO). Access to the entire database was not possible due to data protection regulations. All analyses are based on anonymised administrative claims data that do not allow for direct identification of patients. Due to the anonymisation, the results presented here have no impact on the individuals whose data were used. No ethical approval was required, therefore this study complies with the principles of the Declaration of Helsinki.

#### Data availability

The underlying data are available on request from the Scientific Institute of the AOK (WIdO) (Internet: <https://www.wido.de>, Mail: [wido@wido.bv.aok.de](mailto:wido@wido.bv.aok.de)). The data are not publicly available for data protection or ethical reasons.

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# Prevalence of loneliness among older adults in Germany

## Abstract

**Background:** Loneliness refers to the subjective perception of a mismatch between a person's social needs and their actual personal relationships. In this paper, the prevalence of loneliness in the older population was examined based on current data.

**Methods:** The German Ageing Survey is an ongoing, population-representative study. A total of 4,261 people 50 years of age and older were surveyed in 2020/2021 with regard to their experience of loneliness.

**Results:** Overall, 8.3% of the population 50 years of age and older feel lonely. The findings showed no differences between different age groups over 50 years of age, nor are there gender or educational differences.

**Conclusions:** There was no evidence that older individuals living in private households experience loneliness more commonly than middle-aged individuals. Data from nursing home residents indicate that there may be a higher risk of loneliness.

📌 LONELINESS · SOCIAL NETWORK · SOCIAL RELATIONSHIPS · GERMAN AGEING SURVEY 2020/2021 · AGING · GERMANY

## Introduction

Loneliness describes the perceived gap between a person's social needs and their actual personal relationships, both in terms of quantity and quality of the relationships [1]. Loneliness is a subjective feeling. Therefore, people can feel lonely despite having a large social network and, conversely, objectively socially isolated people do not necessarily feel lonely [2].

Loneliness is associated with a health risk. Several studies have shown associations between loneliness and a higher risk of cardiovascular disease, depression, cognitive impairment and Alzheimer's dementia [2, 3]. In addition, loneliness is associated with increased use of physicians and a higher likelihood of premature death (e.g. [2, 4]).

Previous findings on the risk of loneliness in different population groups indicated that the probability of feeling lonely does not increase across age groups. According to results of the German Ageing Survey (DEAS) as well as an international meta-analysis, the risk of loneliness at an older age is not higher than in the middle of adulthood [5–8]. Studies on the very-old population in Germany complement the findings of the DEAS. They show for the group of 80-year-olds and older that about every 17th to 20th person (5–6%) is lonely at this age [9, 10]. These findings also demonstrate that loneliness is not more widespread among old-age people than among younger age groups. Differences in the figures on the prevalence of loneliness are partly due to the fact that loneliness was measured differ-

ently depending on the study, and people living in nursing homes were sometimes not surveyed. While social networks are often smaller at an older age than in younger age groups [11], loneliness is not more prevalent. Some studies indicated that women and men do not differ in their risk of loneliness starting from middle adulthood and onwards [5], while among children, adolescents and young adults, slightly higher loneliness risks are detected among boys and men [12].

There are also varying and sometimes contradictory results with regard to the educational status. For example, around 7% of highly educated people reported feeling lonely in the DEAS compared to almost 15% of those with low levels of education [5].

Based on nationally representative data from the DEAS, the present study examined the current prevalence of loneliness among women and men, in various age and education groups among the population 50 years of age and older. In addition, the study investigated how the rate of people being at risk of loneliness has changed compared to the pre-pandemic period.

### Indicator

The loneliness rate in the German Ageing Survey (DEAS) 2020/2021 is captured on the basis of an indicator through the self-reports of the respondents in a questionnaire that was completed in written form or online. The DEAS is a nationwide representative cross-sectional and longitudinal survey of people who are in the second half of life and are thus at least 40 years of age. The first survey took place in 1996, and six follow-ups have taken place since then.

In the 2020/2021 survey year, 5,402 people between the ages of 46 and 100 participated in the oral interview; 4,419 of these respondents (82%) also completed the additional questionnaire. The internationally established loneliness measure (LONE scale [1]) used in the questionnaire, which is based on a total of six statements, contains statements such as 'I miss having people around among whom I feel comfortable' or 'I miss emotional security and warmth'. Affirmation of these statements can be expressed on a scale from 1 'strongly disagree' to 4 'strongly agree'. People are classified as lonely if their individual scale mean was greater than 2.5 in the possible value range from 1 to 4. Respondents with missing data were excluded (21 respondents: 11 women, 10 men). In addition, respondents who were younger than 50 years of age (106 respondents: 56 women, 50 men) or older than 90 years of age were excluded (31 respondents: 11 women, 20 men). The final analytical sample consisted of 4,261 respondents between 50 and 90 years of age (2,179 women, 2,082 men).

The 1997 International Standard Classification of Education (ISCED) was used to classify respondents' educational and vocational qualifications [13]. Weighted prevalences as percentages with 95% confidence intervals (95% CI) were presented on loneliness stratified by gender, age and education using methodology that takes into account the stratified sampling of the DEAS. Descriptive results with the respective confidence intervals are presented in tabular form. In addition, a significance test was conducted to test for differences between the groups. A detailed description of the DEAS methodology is presented elsewhere [14, 15].

## 8.3% of the population 50 years of age and older reported feeling lonely in 2020/2021.

### Results and conclusion

A total of 7.8% of women and 8.8% of men in Germany reported feeling lonely in 2020/2021. There was no statistically significant difference between the loneliness rates of women and men. The proportion of women and men who were classified as being lonely was thus at a comparable level (Table 1). Moreover, there was no age-associated trend among the respondents, as there are no statistically significant differences between the age groups. Thus, the loneliness rates were at a comparable level in all age groups. Furthermore, the loneliness rate also did not show a statistically significant difference between different groups of education (Table 1).

The results show that loneliness does not vary between the age groups considered. In contrast, data from a comprehensive UK study indicate that the prevalence of loneliness may be higher among young adults than among older adults [16]. During the COVID-19 pandemic, loneliness increased in the general population, but there was no

additional increase in loneliness among older adults [8, 16, 17]. Additional analyses based on the DEAS demonstrated that, as early as in the winter of 2020/2021, the loneliness rate had declined to a level comparable to 2017. The widespread notion that older people in particular are subject to loneliness is therefore not corroborated on the basis of the present results. It should be noted that the DEAS does not survey people living in nursing homes. A survey of around 1,000 people 80 years of age and older who live in a nursing home in Germany showed that more than one in three people feels lonely (35%) and thus the proportion of lonely people in nursing homes is significantly higher than in the general population [18]. Moreover, living alone should not be mixed up with feeling lonely. The rate of people living alone among the people over 85 years of age is 63%, which is about the same level as among the under 25-year-olds [19].

An explanation for the finding that old age is not per se correlated to higher rates of loneliness is provided by the so-called socioemotional selectivity theory [20]. According to this theory, social needs change with age, so that a smaller number of close relationships is perceived as emotionally satisfactory in old age.

	%	(95% CI)
<b>Total (women and men)</b>	<b>8.3</b>	<b>(6.5–10.5)</b>
<b>Gender</b>		
Female	7.8	(5.5–11.0)
Male	8.8	(6.3–12.1)
<b>Age group</b>		
50–64 years	9.6	(6.7–13.2)
65–74 years	6.1	(4.2–8.9)
≥ 75 years	7.6	(4.4–12.9)
<b>Education group</b>		
Low/medium	8.2	(6.1–10.9)
High	8.5	(5.8–12.5)

CI=confidence interval

Table 1

Loneliness rate by gender, age and education (n=2,179 women, n=2,082 men)

Source: German Ageing Survey (2020/2021)

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**Loneliness rates were at comparable levels for women and men 50 years of age and older. They do not depend on education.**

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**Data protection and ethics**

Participants in the DEAS study provided their informed consent after they were invited and received detailed written information about the aims and procedures of the study. Informed consent covered the voluntary nature of participation, the assurance of data protection and the use of the data gathered exclusively for scientific purposes. An ethics vote was not necessary for the DEAS and was therefore not requested (see the DFG's comments on the necessity of an ethics vote for studies in the humanities and social sciences [21]; none of the criteria for the necessity of an ethics vote – risks for participants, lack of information about the aims of the study, examination of patients – are evident in the DEAS).

**Data availability**

The anonymised and processed data of all completed waves of the German Ageing Survey (DEAS) are available free of charge to the scientific community via the Research Data Centre of the German Centre of Gerontology (FDZ-DZA) as Scientific Use Files (<https://www.dza.de/en/research/fdz/german-ageing-survey>). For data protection reasons, a user contract must be concluded in order to obtain and analyze the data.

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**Conflicts of interest**

The authors declared no conflicts of interest.

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# Prevalence of living wills among older adults in Germany

## Abstract

**Background:** Living wills regulate medical decisions in emergency situations. Those who create a living will can have it registered voluntarily in the Central Register of Lasting Powers of Attorney. Little is known about the general prevalence of living wills.

**Methods:** The German Ageing Survey is an ongoing, population-representative study. 4,185 people aged 50 and older were surveyed about living wills in 2020/2021.

**Results:** 44.8% of people aged 50 and older have a living will, women more often than men (50.1% vs. 39.2%), older people more often than middle-aged people. Educational differences do not exist.

**Conclusions:** Living wills increase the autonomy in medical emergency situations because the patient's wishes are specified in written form. People of all age groups should inform themselves about the significance of living wills and should seek advice about the contents, for example from the general practitioner or one's own health insurance.

PREVENTION · PREVALENCE · LIVING WILLS · GERMAN AGEING SURVEY 2020/2021 · MIDDLE AGED · AGED

## Introduction

Suddenly due to an accident or gradually due to a chronic illness – all people, whether at younger or older ages, can find themselves in a medical emergency situation, in which they are no longer able to communicate their own wishes or to make decisions. In that case, matters can be governed preventively in Germany. While a healthcare proxy or care decree transfers the rights for personal matters (e.g., finances, contacts, etc.) to another person, a living will governs *medical decisions* in emergency situations.

In a living will, any adult person can record in written form, which medical and care provisions they want or deny in the concrete case of certain health conditions (e.g., after brain damage or in the final stage of an incurable, fatal illness), be it examinations, curative treatments, or medical

interventions. It can be determined, for example, whether artificial feeding is to take place, which pain medication is requested, or how one feels about organ donation. The Federal Ministry of Justice additionally suggests specifying further values in the living will, e.g., religious beliefs or attitudes about life and death. When preparing a catalogue of measures, it is suggested to seek guidance from a physician. If the documented patient's wishes are worded in a way that concrete medical situations and measures are addressed clearly, the attending physicians are obligated to follow these wishes. A living will has to be written autonomously and becomes valid by means of personal signature [1]. The notarization of the living will by a notary as well as an official registration in the Central Register of Lasting Powers of Attorney (ZVR) is possible but not

**In 2020/2021, 50.1 % of women and 39.2 % of men aged 50 and older indicate having issued a living will.**

mandatory [2, 3]. Until January 1, 2023, living wills could only be registered in the ZVR as part of an advance directive. In the past year, a total of approx. 5.7 million advance directives were registered, which continues the increase of registered directives of previous years [4–6]. Of the newly registered advance directives in 2022, 77.1 % were combined with a living will. Because there is no obligation to report, however, the ZVR can only hint at the prevalence of living wills [6].

There are only few comprehensive studies relating to the prevalence of living wills in Germany. The collected survey data thereby often originate from selective subpopulations (e.g., patients) and are not representative for the general population. A telephone survey of the German Hospice and Palliative Association (DHPV) among around 1,000 people aged 18 and older showed, e.g., that 43 % of the respondents in Germany have a living will [7]. In another study with around 1,000 people, it became clear that a living will more often existed among patients in intensive care units of a university hospital, who had elective (i.e., planned) surgeries, than among those who required emergency surgery [8]. As reasons for a living will, the survey participants indicated, for example, being afraid of being dependent on the decisions of others, of no longer having autonomy, or of not wanting to get over-treatment.

So far, the ZVR and the research literature does not provide a clear data situation with regard to the prevalence of living wills. In contrast, the present study analyses the current prevalence of living wills among women and men in different age and education groups of the population aged 50 and older on the basis of nationwide representative data from the German Ageing Survey (DEAS).

### Indicator

The existence of a living will was captured in the German Ageing Survey (DEAS) 2020/2021 by self-reported information from respondents in a questionnaire filled out in paper form or online. The DEAS is a nationwide representative cross-sectional and longitudinal survey of people who are in the second half of life and are thus at least 40 years of age. The first survey took place in 1996, and six follow-ups have taken place since then. In the 2020/2021 survey year, 5,402 people between the ages of 46 and 100 participated in the oral interview; 4,419 of these respondents (82 %) also completed the additional questionnaire. The questionnaire contained the question: ‘Have you made one or several of the following written instructions or legal arrangements?’. Among others, the existence of a living will was assessed. The respondents had three response options: ‘yes’, ‘no’, ‘don’t know what that is’. Respondents that selected the response category ‘don’t know what that is’ (12 respondents: 4 women, 8 men) were assigned to the response category ‘no’. Respondents with missing information about the existence of a living will (98 respondents: 56 women, 42 men) as well as respondents younger than 50 years of age (105 respondents: 55 women, 50 men) or older than 90 years of age (31 respondents: 12 women, 19 men) were excluded. The analysis sample thus consisted of 4,185 respondents between the ages of 50 and 90 (2,134 women, 2,051 men). The 1997 International Standard Classification of Education (ISCED) was used to classify respondents’ educational and vocational attainments [9]. Due to a small number of cases with low education level, the groups of people with low and medium education were combined. Weighted prevalences as percentages



**Compared to middle-aged people, older people issue a living will more frequently.**

with 95% confidence intervals (95% CI) were presented on the presence of living wills stratified by gender, age and education using methodology that takes into account the stratified sampling of the DEAS. Descriptive results with the respective confidence intervals are presented in tabular form. In addition, a significance test was conducted to test for differences between the groups. A detailed description of the DEAS methodology is presented elsewhere [10, 11].

### Results and conclusion

In total, 44.8% of respondents report having a living will. There are statistically significant gender differences: 50.1% of women, but only 39.2% of men indicate having a living will. Among both genders, the prevalence of living wills increases significantly across age groups (Table 1). While

31.7% of the women aged 50 to 64 indicate having a living will, already 61.5% among those aged 65 to 74 indicate having one. Among women aged 75 and older, more than three of four women (76.5%) have a living will. With 28.9%, men between the ages of 50 and 64 have a living will significantly far less often than the group of the 65- to 74-year-olds (39.6%); among men, the highest prevalence can also be found in the age group of those aged 75 and older (68.5%). However, whether or not a living will exists does not depend in a statistically significant way on the educational background, neither among women nor among men (Table 1).

While a registration of the living will in the ZVR is voluntary and thus selective, self-reported information from respondents of a random sample provide a potentially more comprehensive picture about the prevalence of living wills in Germany. The nationwide representative data of the DEAS uncover that even during the COVID-19 pandemic period 2020/2021, less than half of all people aged 50 and older report having a living will. Between the ages of 50 and 64, only every fourth person has a living will; however, across age groups, the prevalence of having a living will partially increases significantly. Additional comparisons with the DEAS from 2017 do not show an increase in the prevalence of living wills over the last three to four years (44.7% in 2017 compared to 44.8% in 2020/2021).

The availability and interpretability of the expressed preferences in a patient's living will are extremely important for medical treatments and emergency situations. Since January 1, 2023, treating physicians can access information from the ZVR, if a person is unable to respond and if an urgent medical decision has to be made [6]. However, if a

	%	(95% CI)
<b>Women (total)</b>	<b>50.1</b>	<b>(45.0–55.2)</b>
<b>Age groups</b>		
50–64 years	31.7	(26.2–37.7)
65–74 years	61.5	(53.8–68.6)
≥ 75 years	76.5	(67.6–83.6)
<b>Education</b>		
Low/medium	48.7	(42.1–55.3)
High	53.5	(46.5–60.3)
<b>Men (total)</b>	<b>39.2</b>	<b>(34.8–43.8)</b>
<b>Age groups</b>		
50–64 years	28.9	(23.6–34.9)
65–74 years	39.6	(32.2–47.5)
≥ 75 years	68.5	(56.8–78.3)
<b>Education</b>		
Low/medium	36.7	(30.2–43.7)
High	41.9	(36.3–47.8)
<b>Total (women and men)</b>	<b>44.8</b>	<b>(41.2–48.5)</b>

CI=confidence interval

Table 1

**Prevalence of the existence of a living will by gender, age and education (n=2,134 women, n=2,051 men)**

Source: German Ageing Survey (2020/2021)

## Whether people have issued a living will is independent of the education level.

living will does not exist, if it cannot be found or contains contradictory wording, the patient's assumed will has to be determined and interpreted [1, 2]. To clearly determine the patient's assumed will, the living will can be supplemented with a healthcare proxy, which designates an authorized person for this case [1]. According to data from the DEAS, the majority of people with a living will also have a healthcare proxy (84.9%). To inform about the importance of living wills and to counsel patients with regard to their personal preferences, general practitioners could have an important pilot function. However, the statutory health insurance currently does not pay for counselling about living wills.

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### Data protection and ethics

Participants in the DEAS study provide their informed consent after they were invited and received detailed written information about the aims and procedures of the study. Informed consent covers the voluntary nature of participation, the assurance of data protection and the use of the data gathered exclusively for scientific purposes. An ethics vote was not necessary for the DEAS and was therefore not requested (see the DFG's comments on the necessity of an ethics vote for studies in the humanities and social sciences [12]; none of the criteria for the necessity of an ethics vote – risks for participants, lack of information about the aims of the study, examination of patients – are evident in the DEAS).

### Data availability

The anonymised and processed data of all completed waves of the German Ageing Survey (DEAS) are available free of charge to the scientific community via the Research Data Centre of the German Centre of Gerontology (FDZ-DZA) as Scientific Use Files (<https://www.dza.de/en/research/fdz/german-ageing-survey>). For data protection reasons, a user contract must be concluded in order to obtain and analyse the data.

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### Conflicts of interest

The authors declared no conflicts of interest.

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# Study on Health of Older People in Germany (Gesundheit 65+): objectives, design and implementation

## Abstract

**Background:** The longitudinal population-based study Gesundheit 65+ aimed to close data gaps on health and well-being of older adults in Germany in times of the COVID-19 pandemic.

**Methods:** The target population comprised persons 65 years and older permanently residing in Germany and with sufficient German language skills. Proxy interviews were possible and consent from legal representatives was obtained as necessary in order to enable participation of physically or cognitively impaired persons. A two-stage sampling process, was used to draw 128 primary sample points (PSUs) and within these PSUs sex- and age-stratified random samples were drawn from population registries. A mixed-mode design was applied to contact the study population and for data collection. Data were collected between June 2021 and April 2023. Participants were surveyed a total of four times at intervals of four months. At month 12 participants were offered a home visit including a non-invasive examination. Data on all-cause mortality and information on neighborhood social and built environment as well as health insurance data will be linked to primarily collected data at the individual level.

**Discussion:** Results will inform health politicians and other stakeholders in the care system on health and health care needs of older people in Germany.

HEALTH · OLD AGE · LONGITUDINAL STUDY · POPULATION-BASED · GERMANY · COVID-19 · HEALTH SURVEY

## 1. Background

As in many other countries, the proportion of older and very old people in the population in Germany will continue to rise due to increasing life expectancy and low birth rates [1]. As of 2022 18.6 million people living in Germany are 65 years of age and older, including 6.1 million who are 80 years and older [2]. With increasing age, the probability of illness and the decline in physical and cognitive function increases. The majority of older people today are able to actively participate in social life. However, at a

given chronological age the spectrum of health and functional state in older age ranges from completely unrestricted, independent and integrated in social life to very severely restricted and permanently dependent on support and nursing care. Apart from genetic factors, social and environmental determinants of health largely contribute to the heterogeneity in health and health-related functional limitations among older adults [3, 4].

The COVID-19 pandemic posed major challenges to health care systems worldwide. Older adults, in particular persons 80 years of age and older, and residents of long-

term nursing care facilities were at particularly high risk of severe or fatal COVID-19 in Germany as in other countries [5–8]. In addition, containment measures such as contact restrictions and changes in access and use of health care services affected the entire population, but had different impacts depending on age [9, e.g. 10, 11–14]. Information representative of the population aged 65 years and older is limited.

As part of the nationwide health monitoring in Germany conducted by the Robert Koch Institute (RKI), Gesundheit 65+ was designed to provide current insight into health and well-being of the population aged 65 years and older in times of the COVID-19 pandemic. The study puts a focus on including functionally impaired old and very old people. In contrast to previous health monitoring studies of the RKI [15, 16], the present study therefore applies a previously tested study protocol aimed to include older persons with physical and cognitive impairments [17, 18].

Health in older age was assessed based on primary interview and measurement data collected during the COVID-19 pandemic, which can be linked to data from additional sources like statutory health insurance data or geographic information systems. In detail, analyses of these data will provide insight on:

- (1) health status and well-being based on self-reported data from the cross-sectional baseline survey,
- (2) changes in subjective, physical and mental health, individual and social health determinants and utilization of health care services based on self-reported longitudinal data and

- (3) core indicators of objective physical health as well as physical and cognitive functional status based on cross-sectional data including standardized tests and measurements for groups of older adults with special health care and social support needs.

## 2. Methods

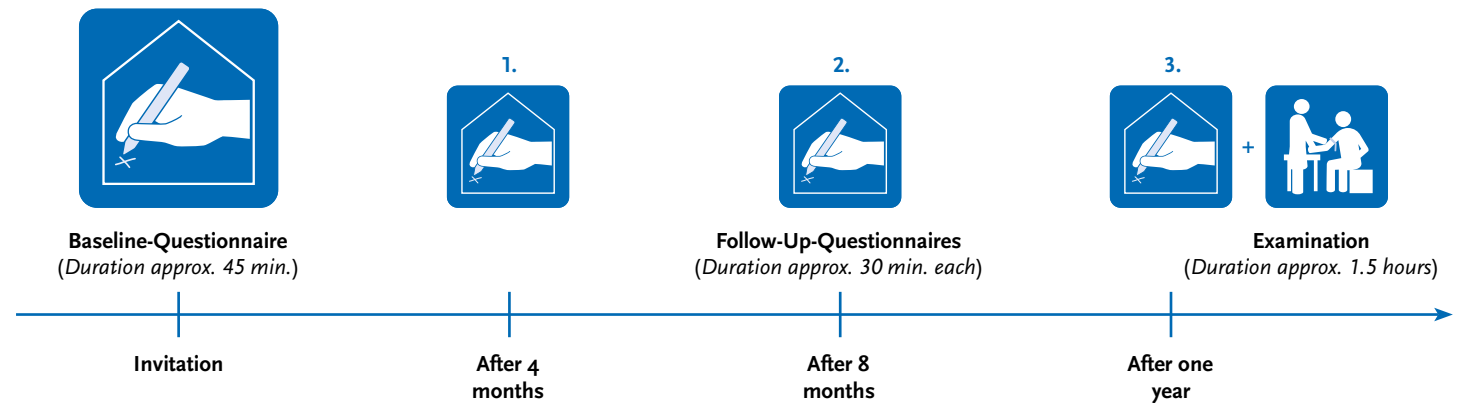
### 2.1 Study design

#### Study design and sample

Gesundheit 65+ is a population-based longitudinal epidemiological study to provide representative data on the health situation of people aged 65 years and older in Germany. A longitudinal survey design was chosen to closely map changes in well-being, health and functional status as well as changes in medical care services and health care services utilization during the course of the COVID-19 pandemic. Data were collected between June 2021 to April 2023 and included a baseline interview survey, which was completed between June 2021 and April 2022, as well as follow-up surveys four, eight and 12 months after the baseline survey (Figure 1). Participants were visited at home for a physical examination and a drug interview at the time of the final follow-up.

The study was funded by the Federal Ministry of Health Germany (Grant No: ZMV11-2518FSB410) and approved by the ethics committee at the Berlin Chamber of Physicians (German: Berliner Ärztekammer, Eth-50/19) and the data protection officer of the RKI. It was conducted in compliance with the data protection provisions set out in the EU General Data Protection Regulation (GDPR) and the Federal Data Protection Act (BDSG). Our data protection con-

**Figure 1**  
**Data collection in Gesundheit 65+**  
 Source: Gesundheit 65+, own description



**Gesundheit 65+ integrates the population aged 65 and older without an upper age limit into the RKI's nationwide examination surveys.**

cept included the use of register-based information and the linkage with publicly available data for non-responder analyses and the search for a telephone number to contact individuals via telephone.

Prior to study enrollment, study participants or their legal representatives provided written informed consent to participate in the study. Participation by means of an online baseline questionnaire was an exception; here, the invited person could also give consent online. In addition, consent could be given at this time for (a) geocoding of the home address for linkage to social and environmental health determinants of the living environment and (b) vital status follow-ups at residential population registration offices (i.e., their survival time). Participants or their legal representatives were informed that the study was voluntary and they could choose to withdraw from the study or any parts of it at any time. Written consent from the invitees or their legal representatives was also required for participation in a non-responder questionnaire/interview at baseline. Oral consent was only possible if the invited individual consented to a telephone non-responder interview.

Prior to health examinations on completion of the study by home visits, participants or legal representatives provided a separate written informed consent. Written informed consent to the linkage of individual ambulatory statutory health care data was also obtained at the home visit.

#### Inclusion and exclusion criteria

The target population comprised persons 65 years and older permanently residing in Germany. We excluded persons not able to understand German language, as well as individuals who had died/moved before the field period started or were untraceable.

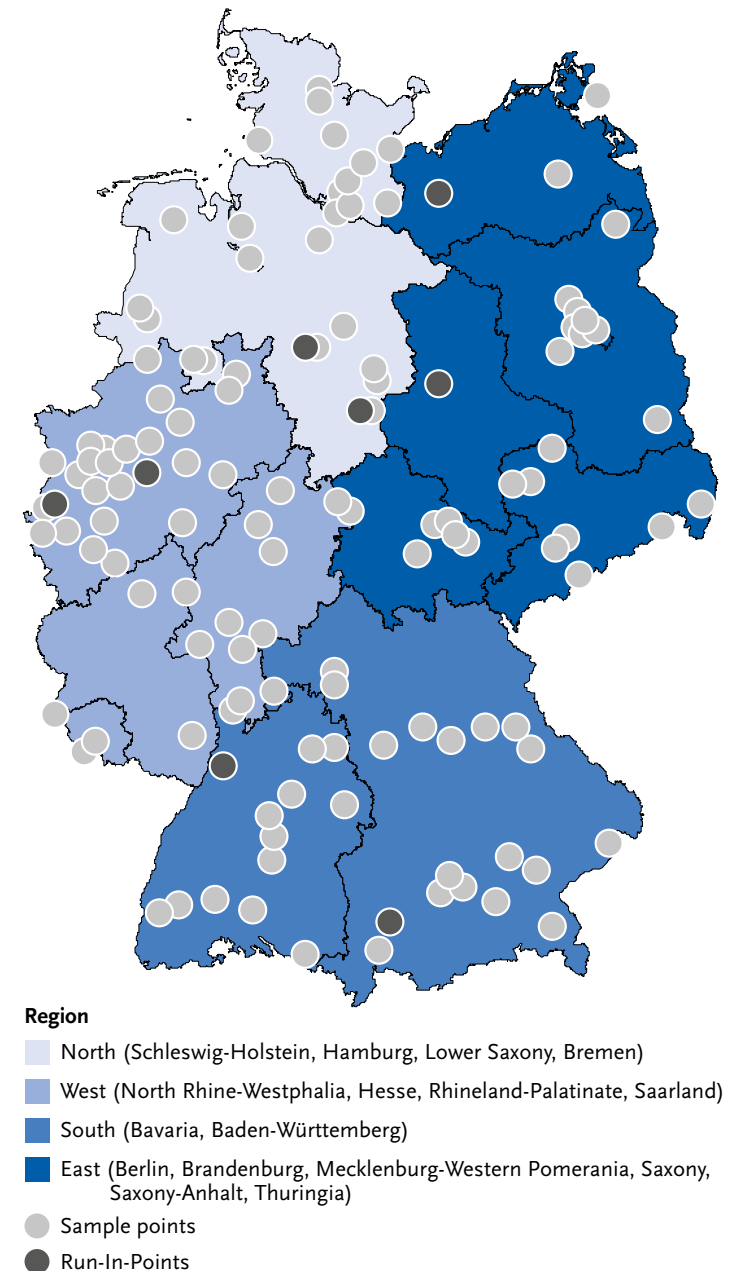
Persons who, e.g. were not able to provide information about their health and to participate in the surveys themselves, could participate by asking a proxy. Persons unable to provide written informed consent were able to participate based on written informed consent provided by their legal representative.

**Figure 2**  
**Primary sampling units of Gesundheit 65+**  
 Source: Gesundheit 65+, own description

The longitudinal study consists of a baseline questionnaire, three follow-up questionnaires and a home visit examination.

### Sampling procedure

A two-stage stratified cluster sampling procedure was applied analogous to the previous population-based RKI health surveys DEGS<sub>1</sub> und GEDA 2014/2015-EHIS [19, 20]. In the first stage, 120 primary sampling units (PSUs) were randomly drawn from all municipalities in Germany in collaboration with the Leibniz Institute for the Social Sciences (GESIS), Mannheim, Germany. Eight additional PSUs were drawn to be used for a run-in period. All 128 selected PSUs are displayed in Figure 2. Random selection of PSUs was stratified based on region and the BIK-10 classification, a regional classification system for Germany [21], in order to adequately represent low-population municipalities and to allow for prevalence estimates in four major regions in Germany. The following regions were considered: North (Schleswig-Holstein, Hamburg, Lower Saxony, Bremen), South (Bavaria, Baden-Württemberg), West (North Rhine-Westphalia, Hesse, Rhineland-Palatinate, Saarland), and East (Berlin, Brandenburg, Mecklenburg-Western Pomerania, Saxony, Saxony-Anhalt, Thuringia). Municipalities with very large populations (e.g. Berlin) are represented by several PSUs. Communities with few inhabitants aged 65+ years were grouped with neighboring small communities belonging to the same stratification cell. In the second stage, within PSUs, sex- and age-stratified random samples of the population aged 65 years and older were then drawn from local population registers applying unrestricted random selection. Stratification by age considered two age groups (65–79, 80+ years).





Various options were offered to enable physically or cognitively impaired individuals to participate.

### Statistical precision and power

To estimate the precision of descriptive prevalence estimates, a corresponding interval of less than 10% of the expected prevalence was used for the width of the confidence interval.

Power calculations showed that a total of 128 sample points and an overall sample size of 2,700 participants would permit estimation of prevalence rate stratified by sex and age group (65–79, 80+ years) at the final follow-up contact (i.e. the examination) with sufficient precision. This calculation assumed comparable numbers of participants by strata and PSU at baseline and, based on previous experience [18], a 32.5% loss from baseline participation to the last follow-up. Cluster sampling underestimates total variability and hence estimation error compared to simple random sampling, because individuals within PSUs are more likely to share study characteristics than individuals directly sampled from the population. The increase in estimation error is quantified by the ‘design effect’ which can be assumed as 1.5 (i.e. 50% more participants are needed, compared to a one-stage sampling design) for the age group 65 and older based on own unpublished analyses of previous RKI population-based health surveys. Due to financial constraints we had to cut down the possible number of examinations per PSU leading to a total number of 1,500 possible examinations at the last follow-up. We repeated our power calculation as described above. Results were similar to the previous calculations. However, confidence intervals for prevalences of 30% and more were slightly wider; the criterion of interval width less than 10% was slightly exceeded here.

## 2.2 Conducting the survey

### Field work strategy (Touring schedule)

In order to avoid systematic (e.g. seasonal or COVID-19-pandemic-related) effects on data collection, the 128 PSUs were randomly grouped into 32 routes. Including a total of four PSUs per route, one PSU was randomly assigned from each of the four regions in Germany and invitations were sent out successively on a route-by-route basis. The sequence of inviting and visiting PSUs for enrollment of study participants into the baseline survey was set in a touring schedule before starting the invitation process.

### Baseline recruitment

A previously developed and tested sequential mixed-mode design [17] was applied to contact the sampled individuals for study participation (Figure 3). In a first step and in addition to a brief personalized invitation letter, the invitees received an information brochure, the baseline paper questionnaire, a consent form, a prepaid envelope for returning the questionnaire, a response form and a small unconditional incentive (pack of flower seeds). The brochure informed invitees on study design (i.e. participation options, planned follow-ups, examination, funding and data protection). After two weeks without response to the invitation, individuals received a postal reminder. The invitation as well as the reminder letter provided a link and a personalized password to an online questionnaire and the offer of a telephone interview as additional options for participation. One week after there was no response to the reminder, trained research assistants contacted the sampled individuals via telephone in order to inform about the study

and the interview options, if a telephone number was available. About 2.5 weeks later, research assistants traveled to the PSUs and tried to contact invitees if no contact or decision on participation had been achieved. The research assistants informed about the study, provided information material (if necessary for other involved persons such as legal representatives or nursing home managers), helped with the questionnaire or offered a face-to-face interview.

Four research assistants visited four PSUs per week (one PSU per assistant), in the following week four other research assistants visited the next four PSUs. It took approximately nine months to complete the baseline survey visiting all 32 routes. Home visits were announced in advance by mail including photographs of the research assistants (50% women; age range: 41–67 years; mean age 54.7 years) who conducted these visits. For identification purposes, research

Gesundheit 65+ collects information on subjective, objective and social aspects of the health of older people with the possibility of linking external data.

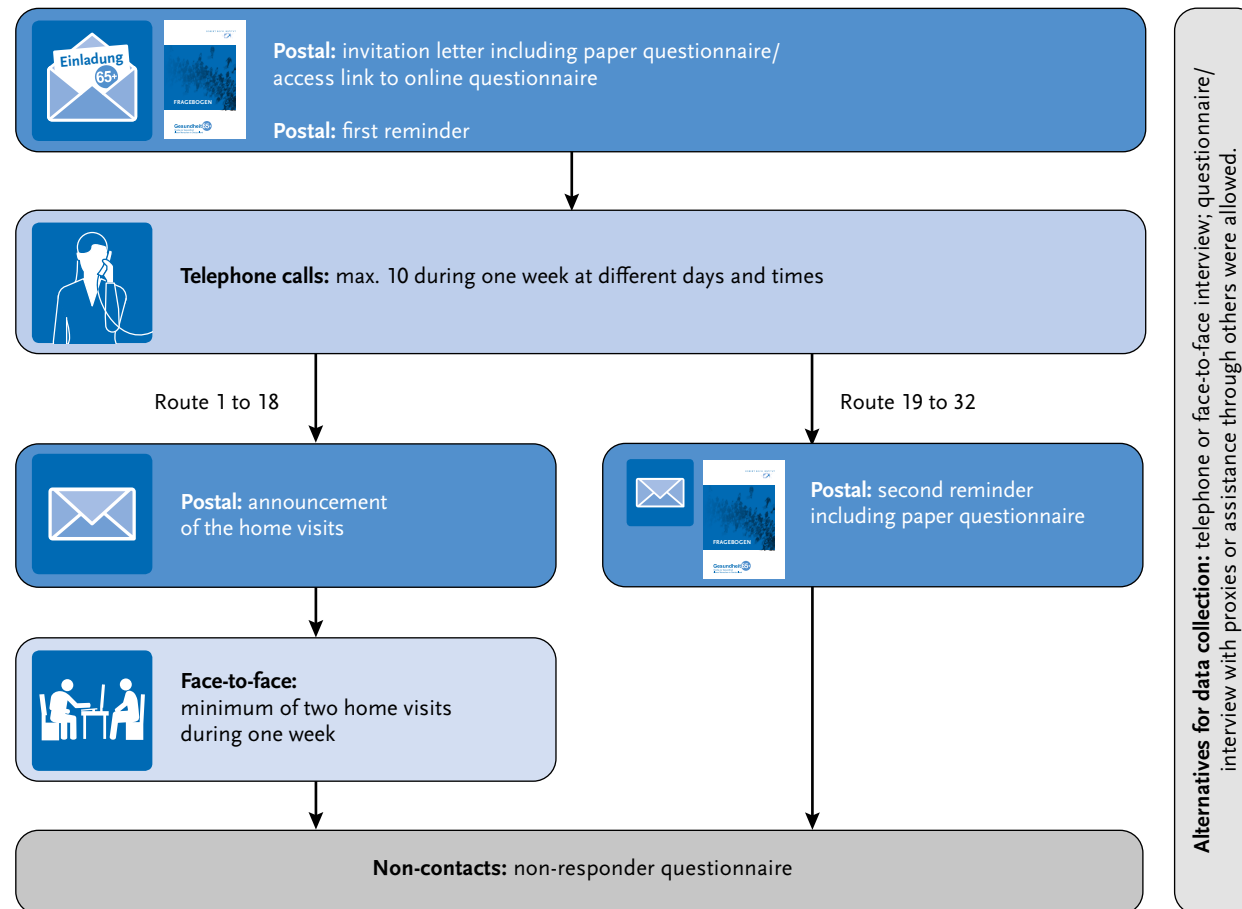


Figure 3

Sequential contact design at baseline

Source: Gesundheit 65+, own description

## Gesundheit 65+ contributes to evidence-based policy advice and public health research in a society of demographic change.

assistants used an official RKI employee identification card. Home visits were stopped after route 18 in November 2021 due to the renewed COVID-19 surge at that time. Instead, from route 19 onwards, sampled individuals received a second postal reminder including the baseline questionnaire and a prepaid envelope. Women 80 years of age and older had turned out to be particularly hard to reach. From route 19 onwards, this group was therefore given another unconditional incentive within the second reminder letter (i.e. monetary voucher of 5 or 10 or 20 €).

The study protocol permitted assisted and proxy participation, i.e. study participants could get help through others such as family or friends with answering the questionnaire/interview. If the participants were not able to take part themselves due to cognitive or physical limitations, they or their legal representatives could authorize other individuals to answer the questionnaire/interview for them (so-called proxy interview).

If invitees or others had further questions at any point, they could contact the study's toll-free service number from Monday to Friday between 9 to 12 a.m. and 2 to 5 p.m. or leave their concerns on an answering machine outside these hours, send their questions via email or could find additional information on the research project's website. Invitees who did not wish to participate could indicate this in writing, by email, by phone or during the home visit.

Individuals who declined to participate as well as non-contacts were asked to answer a short non-responder questionnaire either at the time of study refusal or per mail approximately seven weeks after the initial invitation. In this questionnaire, essential sociodemographic and health-related characteristics were assessed to enable analyses of

non-response and selection bias. Apart from sending back the filled-in questionnaire in a prepaid enclosed envelope, the questionnaire could also be answered by telephone or face-to-face interview during the home visit if desired.

### Public relations work

To raise awareness of the Gesundheit 65+ study, a short study name and a logo were generated and used on all print and online materials. The launch of the study was announced with a national press release (in close cooperation with the RKI press office). In addition, at each of the 128 PSUs, mayors or municipal councils as well as the local press were informed about the study approximately two weeks before the invitation letters were sent out. The purpose of this local and regional public relations work was to increase awareness and trustworthiness of the study.

A detailed study website in German ([www.rki.de/gesundheits65plus](http://www.rki.de/gesundheits65plus)) informs invitees, participants and interested parties about the aims of the study and provides detailed information about the exact process, participation, data protection and study results.

### Re-contacting for the follow-up surveys and the examination

All baseline participants who had not withdrawn their consent for re-contact and who were not deceased according to prior information (e.g. from relatives) were eligible for follow-up contacts. This means that individuals who had not participated in the follow-up surveys and had not completely declined further study participation were also invited again to the next follow-up survey. An address inquiry was conducted at the respective registration office for

persons for whom the invitation letter for a follow-up was returned as undeliverable or who were not reached during the entire re-contacting process, and who had previously consented to this. Any address changes or deaths that became known as a result were taken into account for further re-contacting.

The same field work strategy as for baseline recruitment was used regarding routes and sequence of all invitations. All follow-up contacts were initiated by mail. The mailing included a personalized invitation letter (containing a link and a personalized password to an online version and the offer of a telephone interview), the paper follow-up questionnaire, and a small unconditional incentive (e.g. a pen or four bookmarks). Non-responders were contacted by telephone two to three weeks after invitation and, if no contact or decision on participation was achieved, were sent a reminder letter. Invitees who did not wish to participate could indicate this in writing, by email, or by telephone. In case of a refusal by phone, persons were asked to indicate the reasons for non-participation. Persons stating non-participation by mail and non-responders to follow-up contacts received a letter asking them to indicate the reasons for non-participation according to a checklist via prepaid return mail.

This procedure was the same for all follow-ups. As part of the invitation to the third follow-up, participants were invited to a brief health examination survey during a home visit. An additional brochure informed about the content and procedure of the examination as well as data protection in text and pictures.

From route 24 onwards in order to mitigate effects of self-selection for participation in the examination, only a

reduced number of men aged 80 and over was invited at random for the examination. Up to this point, this group of persons had been reached better than women for the examination and was disproportionately represented in the sample compared to younger men due to the stratified sampling procedure.

### 2.3 Data collection methods, contents and data linkages

#### Content of questionnaires/interviews

In order to lower participation barriers for very old or functionally impaired persons participation efforts were kept as low as possible. We used large print documents to mitigate barriers due to sensory limitations. A mixed-mode data collection design offered a questionnaire on paper (also available as an online questionnaire) or an interview mode. Participants could be assisted by a third person at any time and proxy participation was allowed. Due to data linkage (e.g. linkage with ambulatory health care data) content of health questionnaires/interviews could be focused on health indicators requiring self-reported information. Where possible, questions and instruments were selected from other studies currently conducted by the RKI to enable comparative analyses.

The baseline questionnaire included but was not limited to essential health concepts for older and very old people (e.g. physical and cognitive functioning, mobility, falls, nursing care needs and assistance with basic or instrumental activities of daily living). The selection of indicators was based on a previously developed set of health indicators for the population 65 years and older [22]. In addition, the questionnaire covered the main topics of health: self-per-

ceived health, and health-related quality of life, physical and mental health status, health-related behaviors, utilization of health care and preventive services, social and environmental determinants of health. A special focus was put on the direct and indirect health impacts of the COVID-19 pandemic. The follow-up questionnaires contained selected questions from the baseline questionnaire in order to per-

mit tracking changes in physical and mental health (e.g. self-perceived health, falls, depressive symptoms), health-related behaviors as well as social and psychological determinants of physical and mental health (e.g. social support and loneliness). [Table 1](#) provides an overview of the content of the questionnaires.

Constructs, Measurement	Instrument/Source	Assessment timepoint	Non-responder questionnaire
<b>Health status</b>			
Self-perceived health	MEHM [35, 36]	T0–T3	x
Change of self-perceived health	Self-developed close-ended question	T1–T3	
Chronic disease	MEHM [35, 36]	T0	x
List of age relevant chronic diseases or conditions (past 12 month)	from EHIS [37]	T0, T3 <sup>a</sup>	
Cancer (lifetime) and cancer treatment (past 12 months)	Self-developed close-ended question	T0	
Other chronic diseases with current treatment or impairment of daily life	Self-developed open-ended question	T0, T3	
Pain intensity in the last 4 weeks, duration	SF-36 Health Survey [38], Deutscher Schmerzfragebogen (German Pain Questionnaire) [39]	T0, T3	
Appetite and loss of appetite (past 12 month)	Adapted from Health ABC study [40, 41]	T0, T3	
(Unintentional) weight loss (past 12 month)	According to Fried et al. [42]	T0, T3	
<b>COVID-19 related questions</b>			
Infection	Self-developed close-ended question	T0–T3 <sup>b</sup>	x
Treatment	Self-developed close-ended question	T0–T3 <sup>b</sup>	
Vaccination, intention	Self-developed close-ended question	T0–T3 <sup>b</sup>	x (only vaccination)
Adherence to containment measures	Self-developed close-ended question	T0	
Unmet support related to personal care or household activities	Self-developed close-ended question	T0	
Burdens in the pandemic	Self-developed close-ended question	T2	
<b>Functional impairments</b>			
Difficulty in seeing	From EHIS [37]	T0	
Difficulty in hearing	From EHIS [37]	T0	
Difficulty in mobility (walking, climbing stairs)	From EHIS [37]	T0–T3	x (only walking)
Difficulty in biting and chewing	From EHIS [37]	T0, T3	

Table 1

### Overview over content of baseline, follow-up and non-responder questionnaires/interviews

Source: Gesundheit 65+

T0=baseline, T1=4-month follow-up, T2=8-month follow-up, T3=12-month follow-up, EHIS=European Health Interview Survey, Health ABC study=Health, Aging, and Body Composition Study, MEHM=Minimum European Health Module, SF-36=36-item Short-Form-Health Survey, <sup>a</sup> including cancer, <sup>b</sup> some differences exist in wording

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**Table 1** *Continued*  
**Overview over content of baseline, follow-up  
 and non-responder questionnaires/interviews**

Source: Gesundheit 65+

Constructs, Measurement	Instrument/Source	Assessment timepoint	Non-responder questionnaire
<b>Functional impairments</b>			
History of falls (past 12 months)	Adapted from PROFANE [43]	T0–T3	
Subjective memory impairment	From AgeCoDe-Study [44]	T0–T3	x
Dizziness or vertigo (past 12 months)	Adapted from NHANES [45]	T0	
Urinary incontinence (past 12 months)	From EHIS [37]	T0	
Fecal incontinence (past 4 weeks)	Self-developed close-ended question	T0	
Shortness of breath	MRC Breathlessness Scale [46, 47]	T0	
Activity limitations	MEHM [35, 36]	T0	x
Difficulties with activities related to personal care: basal activities of daily living, ADL	According to Katz et al. [48]; from EHIS [37]	T0–T3	
Difficulties with household activities: instrumental activities of daily living, IADL	According to Lawton and Brody [49]; from EHIS [37]	T0–T3	
Officially recognized disability	Self-developed close-ended question	T0	
Long-term care benefits (German: Pflegegrad)	Self-developed close-ended question	T0, T2, T3	x
<b>Health care</b>			
Type of health insurance	Self-developed close-ended question	T0	
Hospital admissions (past 12 months)	From EHIS [37]	T0–T3	
Emergency care visits (past 12 months)	Self-developed close-ended question	T0	x
Process quality of primary care	Self-developed close-ended question	T0	
Vaccination against flu (last time)	From EHIS [37]	T0	
Number of prescribed medications	Self-developed close-ended question	T0, T3	x
List of health care products	Adapted from NRW80+ [50]	T0	
Use of assistive devices, fitness trackers, wearables	Adapted from Bitkom [51]	T0	
<b>Psychological assessment</b>			
Depressive symptoms (past 2 weeks)	PHQ-2 [52]	T0–T3	
Health related quality of life: single question on energy (past 4 weeks)	SF-12 [53, 54]	T0, T3	
Quality of life: two questions on autonomy and on satisfaction with social participation	WHOQOL-OLD [55]	T0–T3	
Self-perceived current life satisfaction	Adopted from SOEP [56]	T0–T3	
Loneliness	According to R-UCLA [57], from SHARE [58]	T0–T3	
General self-efficacy expectancy	GSE-3 [59, 60]	T0	
Health literacy – Healthcare: two questions on appraise information and understand information	HLS-EU [61]	T0	

T0=baseline, T1=4-month follow-up, T2=8-month follow-up, T3=12-month follow-up, ADL=Activities of Daily Living, AgeCoDe-Study=Ageing, Cognition and Dementia in Primary Care Patients Study, EHIS=European Health Interview Survey, GSE-3=General Self-Efficacy Short Scale-3, HLS-EU=European Health Literacy Survey Questionnaire, IADL=Instrumental Activities of Daily Living, MEHM=Minimum European Health Module, MRC=Medical Research Council, NHANES=National Health and Nutrition Examination Survey, NRW80+=Lebensqualität und Wohlbefinden hochaltriger Menschen in NRW, Repräsentativbefragung NRW80 (German: representative panel study on quality of life and well-being of very old adults conducted in North-Rhine Westphalia, Germany), PHQ-2=2-item Patient Health Questionnaire, PROFANE=Prevention of Falls Network Europe, R-UCLA=Revised UCLA Loneliness Scale, SHARE: Survey of Health, Ageing and Retirement in Europe, SF-12=12-item Short-Form-Health Survey, SOEP=Socio-Economic Panel, WHOQOL-OLD=World Health Organization Quality Of Life -Older Adults Module

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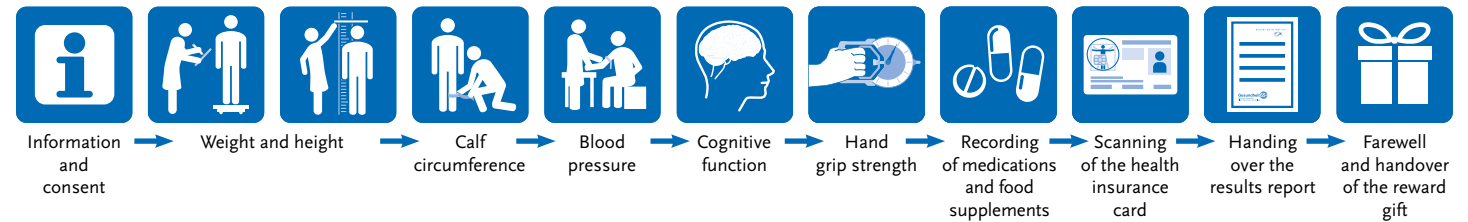
**Table 1** *Continued*  
**Overview over content of baseline, follow-up  
 and non-responder questionnaires/interviews**  
 Source: Gesundheit 65+

Constructs, Measurement	Instrument/Source	Assessment timepoint	Non-responder questionnaire
<b>Health behaviors</b>			
Health awareness: single item	HSC [62]	T0	x
Physical activity and exercise (past 3 months)	From DEGS1 [63]	T0–T3	
Current smoking status	From DEGS1 [64]	T0	
Fruit and vegetable consumption	From EHIS [37]	T0	
Alcohol consumption (past 12 month, past 7 days)	From EHIS [37] and from SHARE [58]	T0	
Body mass index according to self-reported height in cm and weight in kg	From EHIS [37]	T0, T3	
<b>Social environment</b>			
Social support	OSS-3 [65]	T0–T3	
Participation: List of activities	According to NHATS [66]	T0–T3	
Informal care and burden of care	Self-developed close-ended question	T0–T3	x (only informal care)
Frequency of leaving the house (past month)	According to NHATS [67]	T0–T3	
Support with activities related to personal care: basal activities of daily living, ADL	From EHIS [37]	T0–T3	
Support with household activities: instrumental activities of daily living, IADL	From EHIS [37]	T0–T3	
<b>Socio-demographics</b>			
Month and year of birth, sex	Self-developed close-ended question and register-based information	T0–T3	x
Marital status	Self-developed close-ended question and register-based information	T0–T3	
Partnership	Self-developed close-ended question	T0–T3	x
Household size	Self-developed close-ended question	T0	
Type of housing	Self-developed close-ended question	T0, T3	
Education	Self-developed close-ended question	T0	x (only school education)
Country of birth	Self-developed close-ended question and register-based information	T0	
Net household income	Self-developed close-ended question	T0	
Financial constraints (Inability to make ends meet)	From EU-SILC [68, 69]	T0, T3	

T0=baseline, T1=4-month follow-up, T2=8-month follow-up, T3=12-month follow-up, ADL=Activities of Daily Living, DEGS1=German health interview and examination survey for adults (2008–2011), EHIS=European Health Interview Survey, EU-SILC=EU Statistics on Income and Living Conditions, HSC=Health Consciousness Scale, IADL=Instrumental Activities of Daily Living, NHATS=National Health and Aging Trends Study, OSS-3=Oslo-3 Social Support Scale, SHARE: Survey of Health, Ageing and Retirement in Europe

**Figure 4**  
Course of measurements, tests and recordings in Gesundheit 65+

Source: Gesundheit 65+, own description



#### Selection of measurements and tests

Parallel to the final follow-up questionnaire, study participants were invited to take part in a home visit examination with an average duration of 1.5 hours. This enabled even people with limited mobility to participate without great effort. The standardized examinations and tests used have

been tested in previous surveys [16, 18]. Figure 4 provides an overview of the course of the home visit and Table 2 provides an overview of the tests and instruments used. After completion of the examination, participants received written information on their test results and a small gift (material value approx. 5 €).

Component	Device	Measurement
<b>Anthropometric measures</b>		
Height	Portable Stadiometer Seca 213	Height in cm, accuracy of measurement: 0.1 cm
Weight	Personal scale Seca 208	Weight in kilos, accuracy of measurement: 0.1 kg
Calf circumference	Ergonomic measurement tape (Medical product), Seca 201	Circumference in cm on left calf, accuracy of measurement: 0.1 cm
<b>Blood pressure and heart rate</b>		
Resting blood pressure	Mobil-O-Graph®, IEM GmbH	Standardized protocol, three automated measurements in a sitting position after resting
<b>Physical function</b>		
Isometric hand grip strength	Smedley dynamometer, Scandictact, Denmark, 100 kg	Maximum grip strength achieved in four examinations alternating right and left, accuracy of measurement: 0.5 kg
<b>Cognitive function</b>		
Executive function	Letter Digit Substitution Test [70]	Measuring the number of digits correctly substituted within 60s
Verbal episodic memory	Word list from the German language version of consortium to establish a registry for Alzheimer's disease [CERAD, 71]	Measuring the number of correctly recalled words per trial (Trial 1–3 immediate recall, Trial 4 delayed recall)
<b>Medication use</b>		
Current medication use (past 7 days)	„Arzneimittel-Erfassungs-Datenbank“, AmEDa, Medication Recording Database	On-site medication review via a computer-assisted personal interview and automated barcoding
<b>Statutory health insurance data</b>		
Personal health insurance number	Card reader for electronic health cards; software for asymmetrical encryption of personal health insurance number	Linkage to health insurance records such as diagnosis codes and drug prescription up to four years prior to examination

**Table 2**  
Components of the home visit examination at month 12 follow-up  
Source: Gesundheit 65+



### Data linkage

Based on the participants' or legal representatives' informed written consent linkage of primary data collected in Gesundheit 65+ to health-related data from various other sources will be possible. Data from external sources include:

- (1) vital status information obtained from residential population registration offices over a maximum of 20 years to analyze patterns and determinants of all-cause mortality,
- (2) social and built residential environment characteristics obtained through geocoding of the participants' addresses at baseline in order to enable analyses of social and environmental determinants of health, e.g. social area deprivation, health care infrastructure, exposures to noise and air pollution, and
- (3) ambulatory statutory health care data will be linked by an independent trust office for analysis of self-reported health data in conjunction with documented medical diagnoses and health care services provision in collaboration with the Central Research Institute of Ambulatory Health Care in Germany.

### Baseline non-responder questionnaire

A non-responder analysis is essential to assess selection bias in Gesundheit 65+. Therefore, a brief non-responder questionnaire or interview was offered to all baseline non-participants. Proxy participation, e.g. by relatives or caregivers, was possible, if the invitee or her/his legal representative gave consent.

The non-responder questionnaire/interview contained selected questions from the baseline questionnaire/interview as indicated in [Table 1](#). In addition, reasons of non-participation were assessed according to a checklist.

### 2.4 Data processing and expected results

#### Quality assurance

A quality assurance (QA) concept was developed for this study. The QA concept included and defined the following: appointment of topic-based Quality Assurance Officers (QAO), responsibilities for several processes, communication structures within and outside the project, measures such as trainings, Standard Operating Procedures (SOPs), checklists, site visits, and documentation of the measures as well as evaluation of their effectiveness. All measures were supervised by a study-independent QA team established at the RKI.

SOPs were prepared for all steps of the data collection process including checklists for standardized interviews and examinations. Supervised training periods of several weeks were scheduled for study personnel before the start of baseline invitations and the follow-up examination. Training days were scheduled prior to starting first and second follow-up contacts in order to teach the specifics of contacting (e.g. changed order of contact modes, see [Re-contacting for the follow-up surveys and the examination](#)) and contents of the data collection (see [Table 1](#)). Adherence to standardization in interviewing and examination according to SOPs/checklists were verified in advance of data collection and through site visits. If required, additional individual trainings were conducted. In addition, process data,

e.g. on the number and mode of contact attempts per wave, were continuously evaluated and retrainings were conducted in case of deviations according to predefined rules.

Baseline and follow-ups started with a run-in period, i.e. all procedures were tested on the first two routes of eight sample points and could be adjusted as needed.

#### Data management plan

In parallel to the data collection the data management was carried out. The mixed-mode data collection design required different methods for data management that have already been used in previous RKI studies and include the handling of original data, raw data, data correction and finally the provision of analysis datasets. QA actions were implemented into every step of data processing and staff training.

Paper questionnaires were scanned, saved, digitally archived and verified by trained RKI staff. The quality of data entry was assessed via second entry of 10% of the paper questionnaires. In computer-assisted web interviews (i.e. online questionnaire), in computer-assisted personal interviews (i.e. medication review during home visit examination) and in computer-assisted telephone interviews interviewers entered data directly into a software where plausibility checks were integrated by setting valid ranges and logical skips through filters. During baseline home visits or examination visits, face-to-face interviews were conducted paper-based and were entered electronically afterwards as described. Examination data was recorded with computer-assistance or electronically via the specific measurement devices (i.e. blood pressure).

All these raw datasets were combined into one inspection data set. Subsequently, this was used for data editing

with a software syntax to obtain a research dataset. All changes on the datasets were double checked, documented and can be corrected as necessary. The raw data contains only corrections for data entry errors and is kept separate from the fully processed data record. To ensure a uniform procedure during data checking and correcting, general and additional study-specific SOPs were used for work processes in data management and QA. In addition, QA included checking for data completeness at the individual level, extreme values, missing values, compliance with filter questions etc. as well as for consistency and plausibility, accuracy and correctness in terms of content. Responses to open-ended questions were coded, aggregated variables and instruments were created. The research dataset includes all variables that have passed the data privacy check and have been cleared for release by the QA study management. This data is provided with supplementary imputed variables, weighting variables and detailed data documentation (data description, codebooks etc.).

#### Statistical analyses

We developed a statistical analysis plan for stepwise analyses of data based on methodological and public health priorities. This includes the cross-sectional analysis of health data collected during the baseline survey with a particular focus on previously defined core health indicators for older persons [22], longitudinal analyses of intraindividual changes in health status, well-being and analyses of the examination data.

For the statistical analyses a weighting factor was computed in order to correct study results for deviations of the study population from the target population of people 65

years of age and older in Germany as of 31 December 2020 with regard to sex, age, region and community size according to BIK-10 regional classification system for Germany [21]. In addition, the weighting factor will consider deviations in educational level according to the International Standard Classification of Education ISCED 2011 compared to data representative of the German resident population based on the German microcensus 2018 [23]. For the follow-ups, this weighting factor will be multiplied by the inverse of the estimated re-participation probability using appropriate regression methods and predictors to account for loss to follow-up. Descriptive statistics as well as multivariable logistic and other regression analyses for complex survey samples will be applied throughout the analyses of results.

### 3. Discussion

Gesundheit 65+ is the first nationwide population-based health study of older adults in Germany, which is specifically designed to include older and very old people as well as people with health limitations. Including older people in ongoing national health monitoring is crucial to evidence-informed health policy planning and the implementation and evaluation of national health goals, but also challenging [24]. Gesundheit 65+ applied a previously developed and tested mixed-mode contact and data collection design [17, 22, 25]. The intention was to lower participation barriers for older and impaired people who are often excluded or underrepresented in health surveys [17, 26, 27]. Adults 65 years of age and older are heterogeneous with regard to health and functional status, health-related behavior, coping with multimorbidity, social support and participation,

and medical and nursing care needs. Reliable and actionable data on health of older people can only be obtained if people aged 65 and over provide information on their health, living situation and needs [e.g. 28].

Gesundheit 65+ aimed to collect population-representative data that cannot be obtained from any other data sources. In addition to cross-sectional health information obtained during the baseline health interview survey and the health examination as part of the home visit 12 months after baseline, follow-up interviews permit longitudinal analyses of intraindividual variability in health status, health resources and well-being of older adults in Germany in times of the COVID-19 pandemic. Combined with information from routine data, official health statistics and other data linkages, the results will support health policy planning and implementation research to improve the health and well-being of older people in Germany, and not least will contribute to future pandemic preparedness.

#### 3.1 Strengths and Limitations

The strengths of the study are as follows: First, we applied probability sampling and adapted the study design to enable participation of functionally impaired older persons. In order to keep participation barriers and selection bias as low as possible, we allowed assisted and proxy participation in the health interview part of the study and limited exclusion criteria, i.e. to persons with insufficient German language skills. Individuals having a legal representative or who were living in nursing homes were therefore included in our study. As can be seen from the first results of the Gesundheit 65+ study presented in the same issue of the

Journal of Health Monitoring, only 307 people had to be excluded from participation in the study due to this approach. Furthermore, a participation rate of 30.9% was achieved, which is high for this particular age group. Future analyses of the methodology will have to show to what extent the complex recruitment procedure was able to compensate for sampling biases, whether survey data from different survey modes are comparable, and whether there are biases in the examination sample due to the limited offering. Second, our study was carried out in accordance with our QA concept and highly standardized. Members of our research team were extensively trained and continuously supervised during all steps starting with study recruitment to data collection and the data set production.

We also see some challenges and limitations in the realization of this study. First, as other health researchers have already described, our study was affected and challenged by the COVID-19 pandemic [29]. The start of field work was originally planned for March 2020 and had to be canceled due to the first lockdown in Germany. When the study was restarted, the study questionnaire needed to be adapted to the challenges of the COVID-19 pandemic by including questions on infection and vaccination as well as indirect impacts of the pandemic on well-being, health status and health resources. However, this challenge also gave us the opportunity to collect population-based data on changes in health and functional status, health behavior and social health determinants during the pandemic. Due to the pandemic and the following contact restrictions it was necessary to temporarily adapt the study design by focusing on health interview data including a baseline survey and follow-up contacts and postponing the health examination

part. Field work started in June 2021. Baseline recruitment required personal contacts to persons preferring face-to-face interviews and to persons without reaction to written invitations and not contactable by telephone. This was accompanied by high demands on the hygiene concept of the study, which made personal visits much more strenuous for our study team. Despite the hygiene concept, the feasibility of the study (especially the postponed examination) was uncertain throughout the whole study period. For example, face-to-face study recruitment had to be discontinued in November 2021 for the remaining baseline field period, when the SARS-CoV-2 Omicron variant became prevalent, posing a high risk of infection and severe illness to older persons. Future non-response analyses will have to show to what extent this had an impact on participant recruitment (e.g. on the composition of the sample).

Second, our study design is cost intensive. Conducting home visits to older people in Germany over an extended period of time required a large team of research assistants with high levels of commitment and motivation. Home visits are essential to enable older persons with health problems and those who depend on assistance to participate in research studies. However, they also increase the time required for data collection, as study staff must travel to and from the participants' home addresses and set up and take down study equipment. Not all participants prefer a home visit to a study center examination. Examination in a conveniently located study center would therefore be a desirable complementary option to offer, which could be considered in a follow-up study. In the context of our study, however, renting a suitable study site in 128 different cities or municipalities in Germany turned out to be too complex.

Third, even with all the offerings of our study design, very severely impaired people, in particular nursing home residents, remain a hard-to-reach group [30], since nursing home staff and often also legal representatives need to be involved. The COVID-19 pandemic put additional barriers to the inclusion of older persons living in nursing homes. External visitors were granted only limited access even when providing proof of COVID-19 vaccination or a negative rapid test. Currently, roughly 16% of the population aged 65 years and over in Germany receive some degree of nursing care, among these more than one fourth in long-term nursing facilities [31]. In order to routinely include older persons living in long-term care facilities into the national health monitoring, future studies will have to develop appropriate study designs tailored to the specific needs of long-term nursing care residents. At the same time, these studies need to be conducted in parallel to studies of health of older persons in private households in order to provide a full picture [28, 32].

Fourth, the EU General Data Protection Regulation [33] has increased the data protection requirements for scientific studies. In some cases, this may lead to greater uncertainty among invitees, e.g. due to lengthy and detailed data protection statements. Therefore, the comprehensive study brochure includes a passage on data protection in simple language and the complete data protection was added at the end. It was not possible to create a data protection statement that provides comprehensive data protection information to invitees and at the same time is written in simple language that can also be understood by people with reading or cognitive limitations. Future research or national and international research societies will have to show how this can be improved.

Finally, public relations for a nationwide study is an important part of creating trust and informing the public about the study. However, contacting mayors and local media outlets was time-consuming, as contacts in 128 different locations had to be researched and notified. It is not possible to evaluate the extent to which we succeeded in increasing trust and willingness to participate among invitees. In addition, the RKI, as the national public health institute in Germany, was in a strong public focus during the management of the COVID-19 pandemic at that time. This could have led to both a higher and a lower willingness to participate among invitees.

### 3.2 Perspectives

To conclude, Gesundheit 65+ provides a comprehensive dataset on health and well-being of older people in Germany during the COVID-19 pandemic, which will be available as a scientific use file for other interested researchers on request and as part of a research collaboration (expected end of 2024). Study results will be presented to stakeholders in the German health care system, to the scientific community based on conference contributions and publications, and to the public via website information as well as a visualized lay briefing on study results for study participants. To provide continuous health reporting and policy guidance in aging populations, it is necessary to establish a national public health surveillance system for the population aged 65 years and older. For this purpose, a panel is currently being set up at the RKI, into which the data collection of the people aged 65 years and older will be integrated, including regular health examination surveys

in Germany. In addition, there are also efforts to establish health surveillance systems for older people living in long-term care facilities in Germany [34].

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**Data protection and ethics**

Gesundheit 65+ was conducted in strict compliance with the data protection provisions of the EU General Data Protection Regulation (GDPR) and the German Federal Data Protection Act (BDSG). Before commencement of the study, the implementation of the study was approved both by the official data protection officer of the Robert Koch Institute and by the Ethics Committee of the Berlin Medical Association (Eth-50/19). Participation in the study was voluntary and could also be declined in parts. For participation in Gesundheit 65+, either the invited person or her/his legal representative gave written consent. In the context of an online baseline survey, the invited person could also give consent online.

**Data availability**

The authors state that some access restrictions apply to the data. The dataset cannot be made publicly available because the informed consent of the study participants does not cover making the data publicly available. The dataset will be available to interested researchers upon request and as part of a research collaboration (expected to be completed by the end of 2024).

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**Conflicts of interest**

The authors declare that there is no conflict of interest.

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