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BURDEN 2020—Burden of disease in Germany at the national and regional level

All societies are subject to continuous demographic changes and shifts in the spectrum of the diseases affecting public health. These developments are accompanied by population aging. Epidemiological transitions resulting from control of many acute infections have been dominated by a shift towards non-communicable diseases (NCD) and marked changes within the spectrum of NCDs. Stakeholders in public health, including politicians, face the task of assessing whether public health activities have been successful and which diseases, injuries and risk factors require a more targeted approach. The allocation of research funds can depend on assessments of these health issues, as can the planning of major reforms, including those that take place in the health sector. Such assessments need to be based on reliable data and the best available evidence. Moreover, they need to enable diseases to be ranked according to their relative priority and provide information on developments over time. Priority should not only be placed on the incidence or prevalence of diseases but also on the actual impact that the conditions in question have on public health. Although some diseases may tend to have less harmful effects, others might have serious consequences for individuals, if not for the entire population. Even among the most prevalent diseases, there are dif-

ferences in disease severity regarding the consequences.

One approach that takes these challenges into account is the burden of disease. This concept is being prominently implemented as part of the Global Burden of Disease (GBD) study. Based on the International Statistical Classification of Diseases and Related Health Problems (ICD-10) the GBD study uses disability-adjusted life years (DALY) to combine mortality (deaths), frequency (prevalence) and the severity (disability) of a disease into a single coherent summary measure. This enables the relative importance of particular diseases to be compared, and proportions can be attributed to a selected set of risk factors. The project “BURDEN 2020—Burden of disease in Germany at the national and regional level” will use, adapt and expand the GBD study approach. It is aimed at fostering the acceptance of the burden of disease approach in Germany by using a broader data pool as part of the assessment process and by taking into account specific national challenges, such as the implementation of regional analyses. The key benefits of BURDEN 2020 will be:

- The establishment of an informational system and a tool for the visualization of the burden of disease in Germany.

- The evaluation and ranking of important diseases according to their impact on public health.
- The attribution of diseases and injuries to key risk factors.
- Regional analyses to illustrate the benefits of sub-national estimates.
- The establishment of a non-interest-guided basis for health policy planning.

The aim of this article is to describe the potential of the BURDEN 2020 project in more detail. It begins by introducing the burden of disease approach before presenting the potential benefits that can be expected from BURDEN 2020. This discussion is embedded in the context of the experiences already gained by other European countries. Finally, the article outlines the project’s study design before describing its structure and its principal data pool.

Burden of disease: the concept, challenges and previous studies

A concept for quantifying the health of a population

Measuring the health of a population is an essential means of identifying the major drivers of ill health and highlighting potential areas where prevention and in-

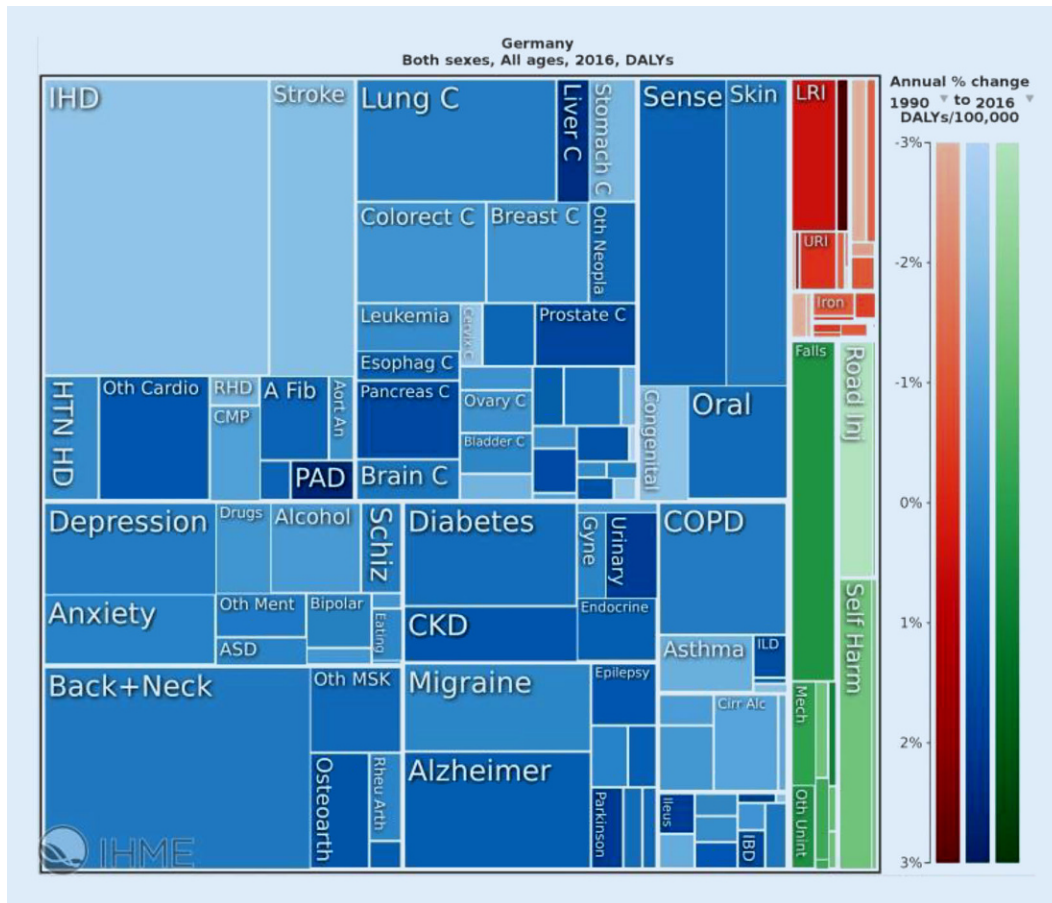


Fig. 1 ◀ Disability-adjusted life years for Germany in 2016 [6]

terventions can yield health benefits for the entire population. The GBD study was introduced in the late 1980s with the aim of measuring global health. It was the first in public health history to shed light on the diseases, injuries and risk factors that contribute to the mortality and morbidity of the global population [1]. The World Health Organization, the custodian of the GBD study, has performed several updates of the global assessment. After the 2010 study was published in a special issue of *The Lancet* in 2012, the Institute for Health Metrics and Evaluation (IHME) took on the task of updating the GBD study [2–4]. Researchers at the IHME developed advanced methods to combine fragmented data and to fill critical data gaps. The results of the GBD study are provided by user-friendly tools that present the data as charts and images. The latest GBD study (2016) provides estimates for 195 countries/territories, and 333 diseases and injuries for the time period ranging from 1990 to 2016 [5]. Since 2015, the IHME has been provid-

ing yearly updates, adding new data to the models and recalculating the results based on the improved methodology.

The GBD study uses several indicators to describe health status and cover the impact of mortality and morbidity. The study uses mortality statistics, information on age at death and life expectancy at this age to calculate what are referred to as the years of life lost due to premature death (YLL). Combined information on disease prevalence is used to estimate the number of years lived with disability (YLD) for calculations of morbidity. In this calculation, the prevalence of single diseases is adjusted for severity using disability weighting. Information on prevalence stems from population-based surveys or routine data, whereas information on the severity distributions and disability weighting is gathered from international surveys [5]. The sum of both YLL and YLD provides a summary measure of population health called disability-adjusted life years (DALYs). This was introduced in the first GBD study and

is used in several global, national and even sub-national assessments to quantify health losses among specific populations.

The GBD study also provides results about the burden of disease in Germany. The results for Germany are not currently broken down into sub-national regional units; however, treemaps are one of the key tools that can be used to browse through the GBD study results (Fig. 1). The outer square represents the total disease burden; the inner segments depict the proportion taken up by non-communicable diseases (blue), communicable, maternal, perinatal and nutritional diseases (red) and injuries (green). The results for Germany show that non-communicable diseases cause the largest burden of disease, with only a small proportion resulting from infectious diseases or injuries. The top three causes of DALYs in 2016 were ischemic heart disease, back and neck pain and diseases of the sense organs.

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BURDEN 2020—Burden of disease in Germany at the national and regional level**Abstract**

Background. Evidence-based policy measures need non-interest-guided information about the health status of a population and the diseases that affect the population the most. In such cases, a national burden of disease study can provide reliable insights at the regional level.

Aim. This article presents the potential of the BURDEN 2020 project and its expected outcome for Germany at the national and regional level.

Methods. The BURDEN 2020 project uses several indicators including years of life lost (YLL) to cover the impact of mortality and years lived with disability (YLD) to cover morbidity. The sum of both is the measure of

population health called disability adjusted life years (DALY).

Results. The study ranks individual diseases and risk factors based on their impact on population health. The burden of disease approach is assumed to be sensitive to subnational differences and may generate immediate benefits for regional planning. The BURDEN 2020 study will pilot a national burden of disease study for Germany that will later be transformed into a continuous data processing and visualization tool. This is done by using, modifying and supplementing the methodology employed by the Global Burden of Disease (GBD) study to better fit the needs of health policy in Germany. This study is

aimed at calculating the disease burden for up to 17 preselected diseases. Furthermore, the estimates of burden of disease are attributed to a selected set of risk factors.

Conclusion. The Burden 2020 study will provide the results of a new, health-related data processing system to the public. This includes a noninterest-guided presentation of the burden of disease (DALY) in Germany at the national and regional level.

Keywords

Burden of disease · Disability adjusted life years · Non-communicable diseases · Health policy planning · Regional prevalence

BURDEN 2020 – Krankheitslast in Deutschland auf nationaler und regionaler Ebene**Zusammenfassung**

Hintergrund. Evidenzbasierte Politikmaßnahmen benötigen unabhängige Informationen über den Gesundheitszustand einer Bevölkerung und die Erkrankungen, von denen die Bevölkerung am meisten betroffen ist. Hier kann eine nationale Krankheitslaststudie zu verlässlichen Erkenntnissen auf regionaler Ebene beitragen.

Ziel. Dieser Artikel beschreibt das Potenzial des Projekts BURDEN 2020 und seine erwarteten Ergebnisse für Deutschland auf nationaler und regionaler Ebene.

Methoden. BURDEN 2020 verwendet mehrere Indikatoren, darunter „years of life lost“ (YLLs, durch vorzeitigen Tod verlorene Lebensjahre), um die Auswirkungen der Mortalität zu erfassen und „years lived with disability“ (YLDs, mit Krankheit/Behinderung verbrachte

Lebensjahre) um die Morbidität abzubilden. Die Summe beider Indikatoren gibt Aufschluss über die Gesundheit der Bevölkerung („disability-adjusted life years“, DALYs).

Ergebnisse. Die Studie ordnet einzelne Krankheiten und Risikofaktoren nach ihrem Einfluss auf die Gesundheit der Bevölkerung. Die Krankheitslast unterliegt regionalen Unterschieden und kann unmittelbare Vorteile für die Planung leisten. BURDEN 2020 pilotiert eine nationale Krankheitslaststudie für Deutschland, die später in ein kontinuierliches Datenverarbeitungs- und Visualisierungstool überführt werden soll. Dazu wird die Methodik der Global-Burden-of-Disease-Studie genutzt und modifiziert, um den Bedürfnissen der Gesundheitspolitik in Deutschland besser gerecht zu werden. Ziel ist, die

Krankheitslast für bis zu 17 ausgewählte Krankheiten zu berechnen. Den Schätzungen der Krankheitslast werden ausgewählte Risikofaktoren zugeordnet.

Schlussfolgerung. Burden 2020 wird die Ergebnisse eines neuen, gesundheitsbezogenen Datenverarbeitungssystems der Öffentlichkeit zur Verfügung stellen. Dazu gehört eine interessenunabhängige Darstellung der Krankheitslast in Deutschland auf nationaler und regionaler Ebene.

Schlüsselwörter

Krankheitslast · Behinderungsbereinigte Lebensjahre · Nicht-übertragbare Krankheiten · Gesundheitspolitische Planung · Regionale Prävalenz

With respect to data availability and quality, the models would ideally be guided by strong national or even sub-national data; however, data are sometimes unavailable for certain diseases, injuries, years or countries. In these cases, the IHME uses mathematical models to overcome the problem of missing data; however, data privacy restrictions mean that the IHME is unable to use all of the available national and sub-national data sources. Claims data, for example, can be helpful in modelling

disease prevalence but are only readily available to the national authorities.

Comparisons of GBD study figures with statistics from the German national level

Due to the study data that were selected and specific modelling processes, certain figures published by the IHME can deviate substantially from Germany's official statistics. This leads to discussion about the external validity of the IHME's figures

and hampers the use of these statistics at the German national level. For example, the GBD study 2015 estimated for Germany in terms of all-cause mortality 899,610 deaths (95% Uncertainty Interval [UI] 850,327–951,882), which is far lower than the 925,200 deaths recorded by Germany's national health reporting system. The German federal health reporting system places a particular focus on diabetes (ICD-10: E10–E14) and recorded 24,400 deaths in 2015 [7]. Despite the fact that the GBD study includes addi-

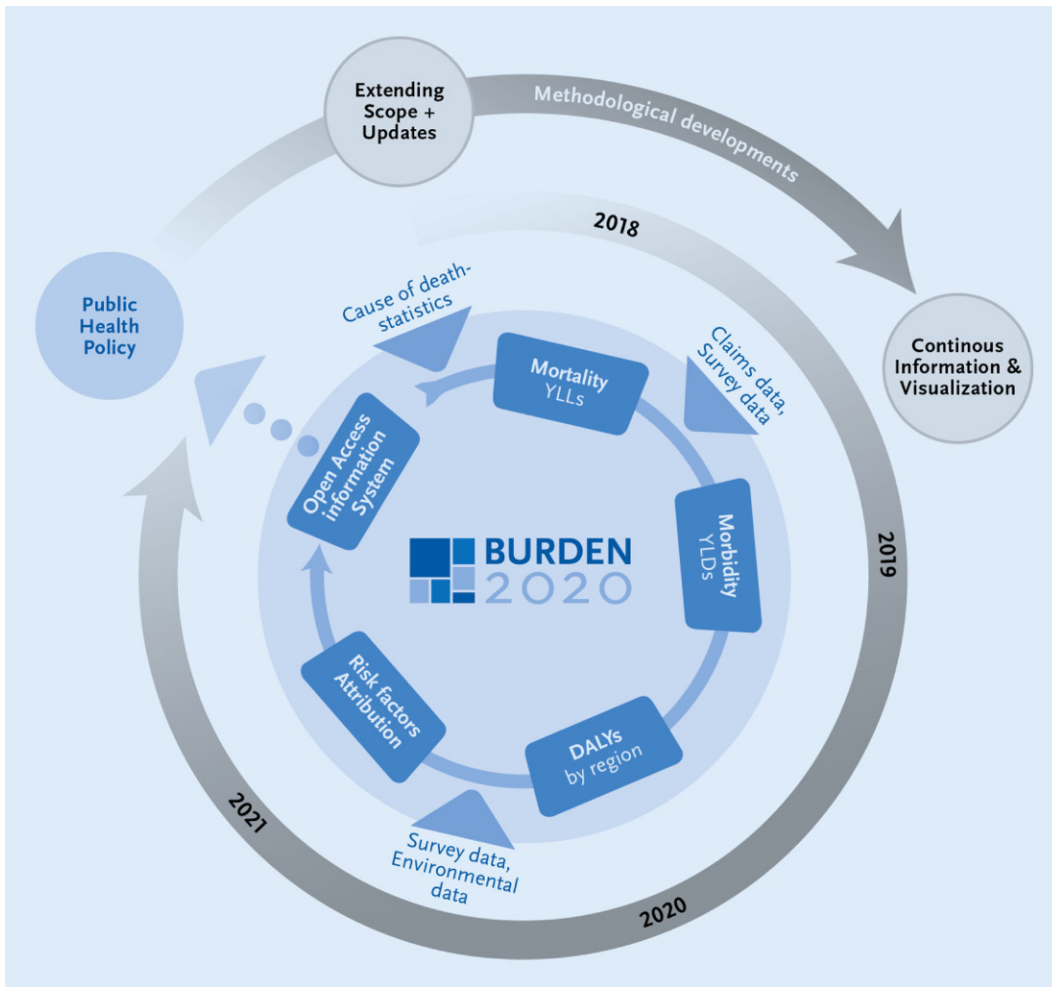


Fig. 2 BURDEN 2020. Initiating and sustaining a national burden of disease study

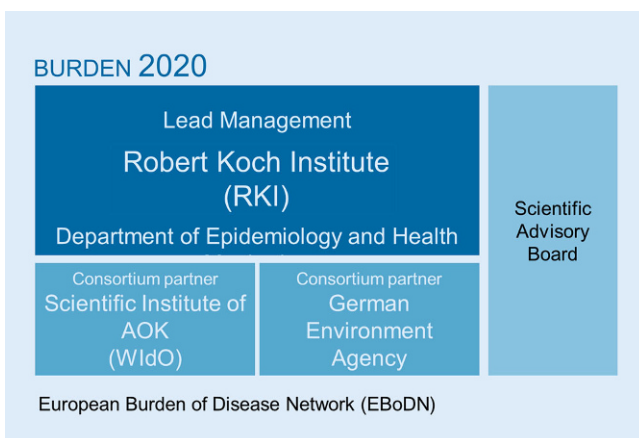


Fig. 3 BURDEN 2020's project structure

tional ICD codes for diabetes, it provided an estimate of just 20,527 deaths (95% UI: 18,831–22,365). As such, the figures from the national level were not within the bounds of uncertainty ascribed to the GBD study's estimate. Furthermore, diabetes-related deaths can be underestimated in the cause of deaths statistics

as complications and comorbidities, such as cardiovascular diseases, are often reported as the underlying cause of death [8–10]. Similar discrepancies can also be found for ischemic heart disease, which is one of the most important causes of death in Germany. According to data from the GBD study, 202,017 people in Germany

(95% UI: 186,868–219,016) died from ischemic heart disease in 2015. The German health reporting system, however, identified 128,230 deaths for the same ICD codes (I20–I25; [7]). One important reason for the differences between the GBD study data and official German statistics is that the IHME performs corrections of its vital statistics data. This is particularly important in cases where deaths were recorded using the wrong ICD-10 codes or “garbage codes” (where deaths are assigned to ICD-10 codes that cannot have been related to the underlying cause of death). The deviations can cause marked differences in DALYs which illustrates the need for methodological adjustments within a national burden of disease study. During this project, different data sources, including sources that are not considered by the IHME, can be analyzed and combined to produce improved estimates of the burden of disease.

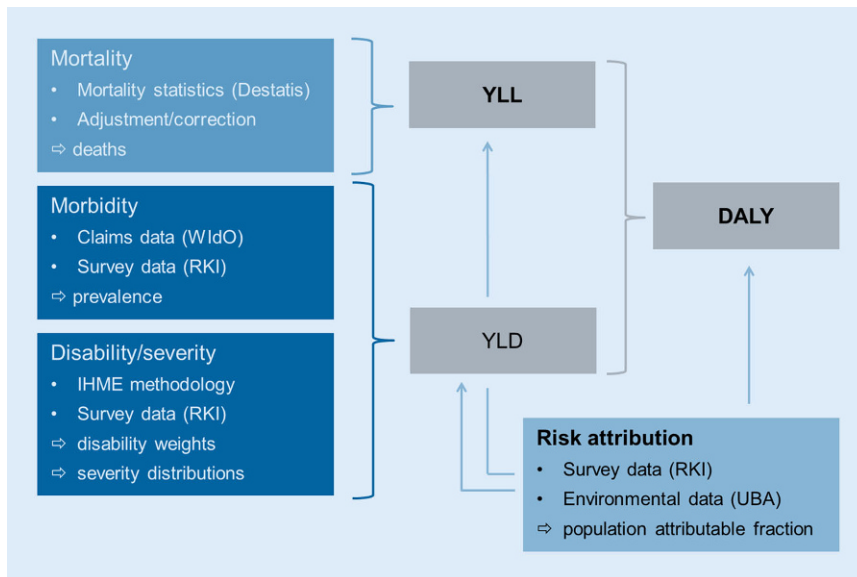


Fig. 4 ▲ BURDEN 2020 data holders and data sources. *Destatis* Federal Statistical Office, *WIdO* Scientific Institute of AOK, *UBA* German Environment Agency

Experience with European studies of the national burden of disease

In addition to the fragmented data pool and the fact that differences between the GBD study and national statistics and studies are sometimes hard to grasp, the GBD study does not provide estimates on sub-national level for many European countries. In order to increase the external validity and acceptance of the figures provided by the IHME, several countries have established their own studies on the burden of disease. Some have conducted their research (including the calculation of sub-national estimates) in close cooperation with the IHME and have strictly followed their methodology (this is the case with England and Norway; [11, 12]). Public Health England has already undertaken two assessments. The first was conducted in 2013 and presented figures for nine English regions and areas of social deprivation [12]. The more recent 2016 study provided figures for 150 English local authorities and is part of the GBD 2016 study [13]. Other countries have already or are currently running their own studies based on adapted methodologies (these include countries such as the Netherlands, Scotland and Belgium) [14–16]. The Dutch National Institute of Public Health and the Environment (RIVM) has long-standing experience in

performing burden of disease studies using its own approach. The 2018 report of the Dutch Public Health Foresight Study presented burden of disease estimates for 2015–2040 based on an updated methodology and improved data [17]. The results from the study provided information for the Dutch Ministry of Health’s 4-year policy plan.

The aims and scope of BURDEN 2020

Rationale and project development

The growing interest and use of the burden of disease approach led to the initiation of BURDEN 2020 in Germany. The project was preceded by a workshop that took place in December 2015 [18] and a second workshop that took place in April 2018. Both workshops were used to identify data requirements and to discuss methodological challenges together with national and international experts from the field. In addition, BURDEN 2020 also responds to challenges that are emerging within the German health system. The current attempts to implement health reforms are facing challenges to ensure that health care planning becomes more closely geared to the morbidity and disability patterns of the pop-

ulation and more responsive to regional needs. The German health system currently lacks a decisive tool that could be used to meet these demands: whereas sub-national analyses of prevalence or incidence of single diseases are available [19–23], a comprehensive, non-interest-guided presentation of the burden of disease, which would enable reliable and regionalized analyses of public health is not yet available. Thus, BURDEN 2020 is based on the assumption that ranking individual diseases and risk factors according to the impact that they have on population health would provide a very useful tool to policy makers and other public health stakeholders. Furthermore, the burden of disease approach is presumed to be sensitive to sub-national differences and viewed as having the capacity to generate immediate benefits for regional health policy planning, evaluation and implementation. Over the next three years, BURDEN 2020 will pilot a national burden of disease study for Germany. In the future, this study is to be transformed into a tool that enables continual data processing and visualization (■ Fig. 2). This is to be done by employing, modifying and supplementing the methodology of IHME in cooperation with international partners so that it more closely reflects the needs of health policy and planning in Germany.

In order to achieve the objectives set out above, in 2017, funding was applied for from the German Federal Joint Committee’s Innovation Fund (Innovationsausschuss beim Gemeinsamen Bundesausschuss), the application was approved in 2018 (Grant no. 01VVF17007). For the pilot, BURDEN 2020 will focus on a selected list of chronic conditions and disease groups serving as model conditions for chronic diseases of high public health impact. The project will take into account demographic developments that are marked by a clearly defined spectrum of diseases, risk factors and their consequences. These aspects pose the main challenges for the future development of the health care system in Germany. The analyses are aimed at initially calculating the disease burden caused by ischemic heart disease, low back and neck pain, stroke, tracheal,

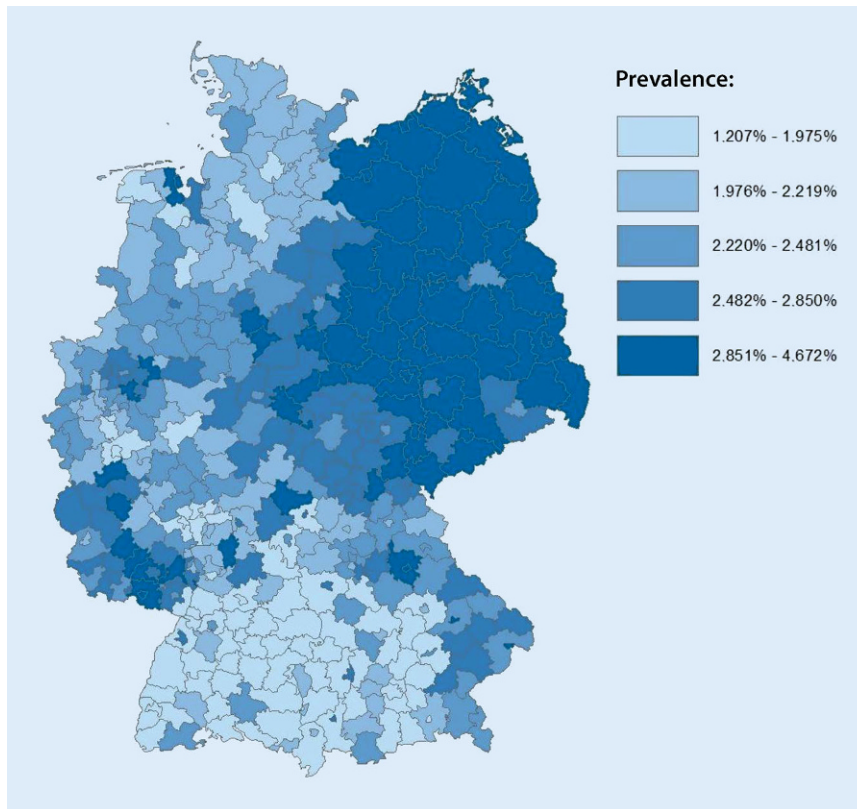


Fig. 5 ▲ Administrative prevalence of known dementia by districts and independent cities in Germany in 2016 (not adjusted for age and gender). Source: AOK claims data, own calculations

bronchial, and lung cancer, Alzheimer disease and other dementias, diabetes, chronic obstructive pulmonary disease (COPD), falls, depressive disorders, other cardiovascular and circulatory diseases, colon and rectum cancer, anxiety disorders, breast cancer, alcohol use disorders, lower respiratory tract infections (mainly pneumonia), hypertensive heart disease and prostate cancer. The results of the 2016 GBD study for Germany show that a focus on these diseases will cover at least a total of 51.9% of overall DALYs that occur in the country. When calculating mortality (deaths and YLL), it should be straightforward enough to extend this spectrum to achieve full coverage of the IHME's causes of death list. The calculations on morbidity (prevalence and YLD), however, will initially remain limited to selected diseases.

Partners, data and methodological challenges

BURDEN 2020 is being jointly carried out by three institutions (■ Fig. 3). The

consortium is led by the Robert Koch Institute (RKI) Department of Epidemiology and Health Monitoring. The Scientific Institute of the AOK (WiDO) and the German Environment Agency (UBA) are equal partners. The project is accompanied by a scientific advisory board that will be involved in important decisions such as the selection of diseases and risk factors and the regional level at which estimates of burden of disease are feasible and appropriate. BURDEN 2020 is also embedded in the European Burden of Disease Network (EBoDN), a network of WHO, IHME and national representatives with experience in the burden of disease, which aims to promote scientific debate and the exploration of methodological developments [24].

The project starts by calculating the mortality associated with the burden of disease. Individual data from cause of death statistics in Germany held by the Federal Statistical Office (Destatis) are used for these mortality analyses. These data contain information on age, gender, place of residence and the underlying

cause of death. The data are accessible via the Research Data Centres of the Federal Statistical Office and the Statistical Offices of the Federal States (*Länder*); these data also form the basis of the calculations of the number of deaths and YLL (■ Fig. 4).

The three participating institutions are not only partners when it comes to morbidity and risk factor analysis, but they are also data holders and provide important information for the assessment of the national burden of disease (■ Fig. 4). As a scientific institute belonging to the largest association of statutory health insurance providers in Germany, WiDO holds data on around 26 million people who are insured by the AOK (Allgemeine Ortskrankenkasse). Anonymized data including medical diagnoses, medical treatment, drug prescriptions and disease management programs enable the assessment of the prevalence of diseases, regional disaggregation and YLD [25]. Advantages of routine data even include the possibility to detect rare diseases, capture groups of the population that are difficult to reach in surveys (like elderly or people in institutions) and generate information on the presence of comorbidities or multimorbidity. Once the specific characteristics of AOK insurees have been accounted for, the results are to be extrapolated to the German population as a whole.

Furthermore, the health interview and examination surveys conducted by the RKI as well as the German cancer registry data constitute an important supplement to claims data. Survey data enable undiagnosed morbidity to be accounted for as part of the calculations [26, 27]. Information on the number of people diagnosed with cancer that is provided by the German Centre for Cancer Registry Data [28] at the RKI will be used as an additional data source for the calculation of cancer prevalence.

It is essential that each of the selected diseases and their sequelae are correctly defined for BURDEN 2020; however, defining disease using claims data poses a challenge because the case selection criteria that ultimately need to be applied must be carefully tested and brought in line with the definitions used by the GBD study. This includes deci-

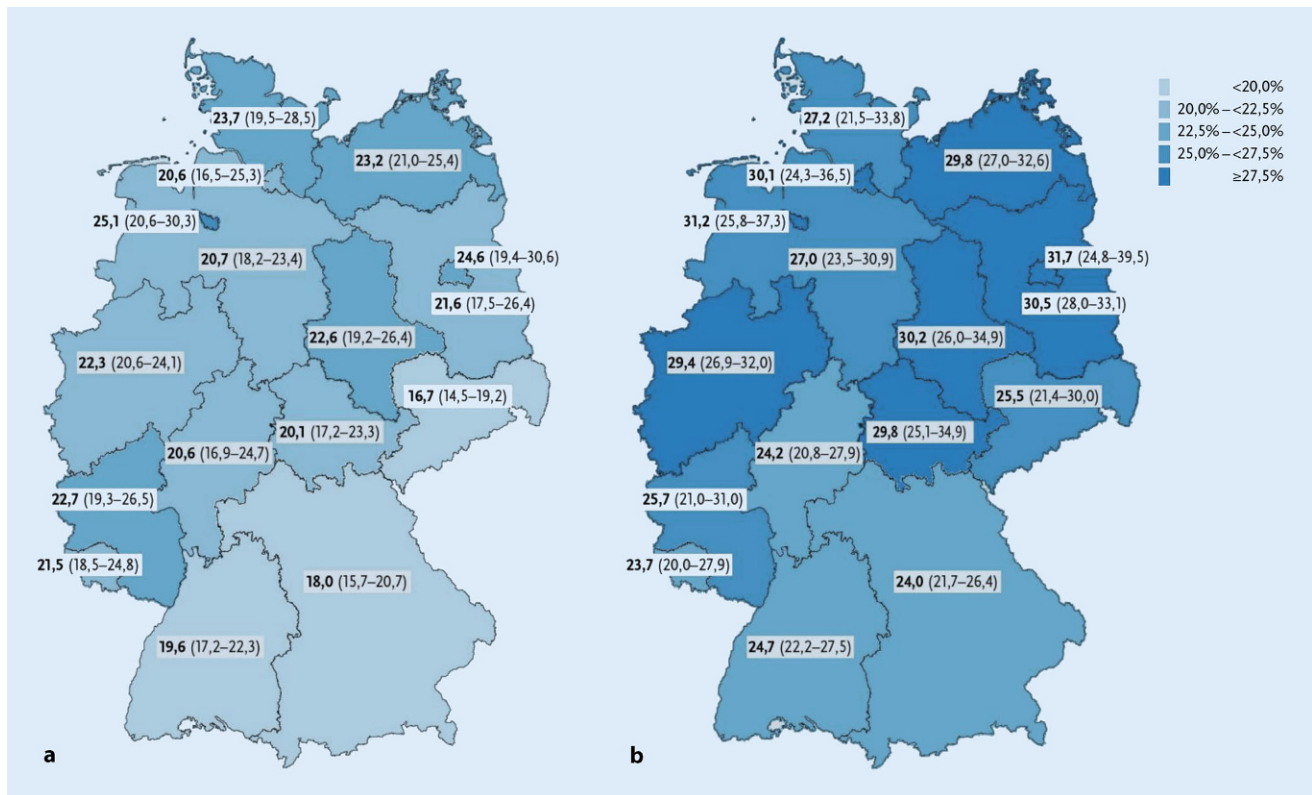


Fig. 6 ▲ Current smokers according to gender (a female, b male) and federal state, confidence intervals in brackets. (Source: GEDA 2014/2015-EHIS [31])

sions as to whether the ICD codes used in the GBD (on causes) can be retained or should be adapted to the specific requirements found in Germany. These challenges mean that BURDEN 2020 has to be initially limited to a selection of diseases.

In general, BURDEN 2020 uses the disability weights and severity distributions applied in the GBD study. It is also planned that BURDEN 2020 takes into account not just single diseases, but also the comorbidities they are most frequently associated with. Regarding the severity of disease, the health interview and examination surveys conducted by the RKI may again constitute an important supplement that enable empirical measurements of severity distributions that are more applicable to the situation in Germany.

The data used to calculate the DALYs are supplemented by information on the distribution of risk factors in the population. Behavioral risk factors will be analyzed based on the health interview and examination surveys conducted by the

RKI, whereas environmental risk factors will be analyzed using data from the German Environment Agency (UBA). Population attributable fractions will indicate which proportion of the disease burden can be attributed to specific risk factors (■ Fig. 4). As a starting point, this is envisaged for smoking, tobacco consumption, alcohol consumption, low levels of physical activity and selected nutritional risks as well as passive smoking, particulate matter, nitrogen dioxide and lead exposure.

With respect to regional analyses [29], the aim is to estimate disease burden at a level below that of the 16 German federal states as seen in ■ Fig. 5 for the prevalence of dementia estimated from claims data. Data are available for many indicators at the federal state level (see the example for current smokers in ■ Fig. 6), but it might be challenging to break down the results below this level. Nevertheless, there is a fundamental need for regional information when informing authorities and other stakeholders and supporting the planning of supply structures and pre-

vention. For example, there are 96 planning regions in Germany and 401 districts and cities below the federal state level. Taking into account aspects such as data availability, data protection and methodological feasibility, BURDEN 2020 will need to answer the question as to which regional level is appropriate for estimates of disease burden. In addition, the RKI's German Index of Socioeconomic Deprivation (GISD) offers the opportunity to relate the regional burden of disease to people's living conditions [30].

Expected outcome

At the end of the project period, BURDEN 2020 will provide the results of its new, health-related data processing system to the public. The merge of fragmented data sources will create a basis with which to provide epidemiological information and information for health policy decisions. This includes a non-interest-guided presentation of the burden of disease (DALYs) in Germany and its regions for a selection of what are

predominantly non-communicable diseases. Furthermore, it will also include a presentation of the connection of the burden of disease to a selected set of risk factors. The calculations will be accessible free of charge via a permanent open access informational infrastructure provided by the RKI, both electronically and in the form of health reports and expert contributions. Therefore, it will constitute an information service for policy makers and other public health stakeholders. In the future, the project is to be expanded to assess other diseases and risk factors and its methodology is to be tailored to the specific needs and demands found in Germany. The long-term goal is to provide a differentiated and continuous calculation of disease burden based on the available data in Germany (Fig. 2). Moreover, the project is to enable forecasts and evaluations to be made that deliver an appraisal of the future framework conditions for health policy planning.

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Compliance with ethical guidelines

Conflict of interest. A. Rommel, E. von der Lippe, D. Plaß, A. Wengler, A. Anton, C. Schmidt, K. Schlüssel, G. Brückner, H. Schröder, M. Porst, J. Leddin, M. Tobollik, J. Baumert, C. Scheidt-Nave and T. Ziese declare that they have no competing interests.

This article does not contain any studies with human participants or animals performed by any of the authors.

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