A Guide to National Burden of Disease Analysis

Bloomberg Philanthropies

DATA FOR HEALTH INITIATIVE

Vital Strategies

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GLOSSARY OF TERMS

Global Burden of Disease: Also known as GBD.
It outlines the global distribution and causes of a wide range of serious diseases, injuries, and health risk factors worldwide yearly, and results are available by country.

Local data: For the purpose of this document, local data refers to country data.

Modifiable data: These are the data that, during the process of the burden of disease study, must be adjusted and modified with the data from the morbidity or mortality information systems of the country and, thus, have information that approaches the epidemiological situation. They can be modified since the decision must be made whether to modify (fully or partially) or not those data that are already estimated for the country.

Non-modifiable data: These are data that should not be adjusted or modified during the process of the burden of disease study for the country, since they are already available and estimated.

DisMod: A software program that allows to obtain a set of consistent estimates of incidence, disability duration and mortality from a model based on the dynamics of diseases. The software is available at the WHO website. There is also another version called DisMod- MR developed by IHME.

Disability: It refers to any short- or long-term health impairment, other than death.[1,2,3]

A subject matter expert: An international, national, or local professional with some government or academic link which has expertise and experience in a particular disease.

Official information source: Information from Ministries or Secretariats, Institutes, Departments, Divisions, or Units of the Government.

Nonofficial information source: Information from organizations not linked to the government of a country. Example: Universities, Cooperation Agencies, Non-Governmental Organizations, etc.

IHME: The Institute for Health Metrics and Evaluation. It is an independent global health research center at the University of Washington.

Synthetic indicator: It is that indicator that summarizes in one single indicator mortality and morbidity information. In the case of the burden of disease study, the synthetic indicator is the disability-adjusted life year (DALY).

Executive Report: A document that reports the results of the burden of disease in a high-level format that will facilitate proper decision making.

Summary measure: It is the measure that from the epidemiological standpoint summarizes the health status of a population.

Sequelae: Effects of an illness or injury.

1 Leonardi M, Bickenbach J, Ustun TB, Kostanjsek N, Chatterji S, and the MHADIE Consortium. The definition of disability: what is in a name? Lancet 2006; 368: 1219-21.

2 Thomas C. How is disability understood? An examination of sociological approaches. Disabil Soc 2004; 19: 569–83.

3 Murray C, Evans D. Quantifying individual levels of health: definitions, concepts, and measurement issues. In: Health systems performance assessment: debates, methods and empiricism. Geneva: World Health Organization, 2003: 301–18.

INTRODUCTION

The burden of disease is a methodology that measures the health status of a population in a synthetic indicator - disability-adjusted life year (DALY) - that compiles in a single measure both morbidity and mortality information.

At global level, there has been a collective effort to obtain statistical and epidemiological information in order to produce and report consistent DALY estimates for each of the countries. The Institute for Health Metrics and Evaluation (IHME) website currently offers comparisons of DALYs across countries and regions of the world, providing information not only on the total number of DALYs, but also on the diseases that cause them.

However, although the information estimated by the IHME can help provide an approximation of what would be happening in each country, it is still necessary to make some adjustments that allow us to better understand the epidemiological situation of the country. To this end, it is necessary to review the estimates of the parameters of incidence and mortality in order to adjust them with national data.

The purpose of this document is to present a guide to the study of the burden of disease in the countries through the estimation of disability-adjusted life year - DALY based on national data.

Suggestions and recommendations in this document are primarily intended to guide teams in Ministries or Secretariats of Health in developing their own burden-of-disease analysis for a national level. Nevertheless, the recommendations are also valid if they are to be applied to sub-national levels.

I CONTEXT

The burden of disease is a methodology that approaches and measures the health-disease process in a more comprehensive way, because it has a synthetic indicator that brings together fatal and non-fatal outcomes. Therefore, the concept of health is built in terms of functionality, which encompasses multiple health domains such as mobility, pain, affect and cognition[4].

The burden of disease measures the loss of life (without disability) as a result of death, illness or injury. That is, it quantifies the extent of health loss due to specific illnesses and injuries.

Because it contains a summary measure, the burden of disease provides a comprehensive overview that helps decision makers, researchers and citizens understand what the most important problems are and whether they are improving or worsening.

It involves a holistic, descriptive, inclusive, and comparative approach, intended explicitly to report on the health status of a population to help determine health priorities. The burden of disease analysis is a systematic scientific effort, based on the initial work of Murray and López.[5]

The Burden of Disease study offers a different way of analyzing health losses, as it provides a composite indicator that integrates:

- damage caused by premature death and
- those caused by illness and disability with different levels of severity from one or more diseases at the same time.

Initially when the burden of disease studies appeared, the first results were estimated for global sub-regions, now it can be seen that there are estimates for each country and even for sub-national levels. **It is necessary for each country to define the scope of application.** At first, its scope will be national and then it will be assessed to apply the study to sub-national areas.

4 Murray C, Evans D. Quantifying individual levels of health: definitions, concepts, and measurement issues. In: Health systems performance assessment: debates, methods and empiricism. Geneva: World Health Organization, 2003: 301–18.

5 Murray C, Lopez AD. Global and regional cause of death patterns in 1990. Bull World Health Organization 1994;72(3):447-480

I IMPORTANCE OF THE BURDEN STUDIES

For many years, the paradigm of the relative importance of diseases according to the number of deaths they cause was valid. This approach implicitly assumed that people who did not die were "healthy". However, it was increasingly observed that many diseases or conditions were not fatal but accounted for a large loss of health, leading to significant demands on health systems (e.g., chronic depression or paralysis caused by polio)[6].

It was also common practice that health losses, either from death or illness, were estimated separately. On the one hand, deaths were quantified and on the other, cases of illness and/or disability. However, due to the intrinsic nature of the event, they were reported separately since they could not be aggregated. In other words, the leading causes of death and leading causes of morbidity were presented on separate lists.

These situations determined the need to have a unique and not segmented perspective (on one hand mortality and on the other morbidity) about the health level of a population. Consequently, the importance of understanding the real dimension of the causes that contribute to the loss of health was acknowledged, through the use of a single indicator that measures the health-disease process.[7]

Advantages

It has been nearly 30 years since the first burden of disease study. Over this time, there has been not only a better understanding of the method, but also a greater access to its information.

As a result, the reason is currently obvious, and countries are advised not only to explore and use available burden-of-disease data, but also to try to build one.

However, it is necessary to remember the reasons for its existence from the standpoint of its usefulness or advantages both directly and indirectly.

The importance of measuring non-fatal outcomes

The improvement in the therapeutic management, as a result of scientific and technological progress, for various diseases and especially for chronic diseases, is changing how health status should be measured and evaluated. In addition, the impact of the epidemiological transition in many low-income countries must be assessed, causing chronic conditions to become increasingly common. These situations, together with the reduction of mortality, show the importance of measuring non-fatal health losses.[8]

6 Work Bank. Investing in health World Development Report. 1993

7 Murray CJ, Salomon JA, Mathers CD, Lopez AD. Summary measures of population health: concepts, ethics, measurement and applications. Geneva: WHO, 2002.

8 Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017.

Direct Advantages

From the epidemiological standpoint

- Understand and describe the real global extent of health status in terms of total health loss in a given population and be able to compare it with other populations and over time. [9],[10]
- Learn precisely which diseases, injuries, and risk factors contribute most to health loss in a given population.

From the health management standpoint

- Contribute as a technical input in the identification of health priorities, which is the main reason for the burden of disease studies.

Therefore, it is necessary to make some remarks about the identification of priorities, as it is a technical-political, dynamic and wide process that requires the convening and selected participation of different stakeholders. This document does not deal with the political process, but as far as the technical component is concerned, it should be noted that it requires solid inputs that contribute to and feed the determination of priorities. Also, the objective of prioritization must be clearly established, which will provide guidance on what information is needed. For example, the sources of information will be different if something very specific is to be prioritized, such as the need
for resources for an outpatient care service, compared to something broader, such as the definition of a portfolio of healthcare services within the universal insurance framework. For the first case, it may be necessary only to analyze the demand and flow of health care (morbidity). While for the second case, which is more focused on the definition and planning of health policies, the sources of morbidity alone are insufficient inputs to understand the real dimension of health status.

Consequently, as previously mentioned regarding the determination of health priorities, it will be necessary to consider a unified indicator such as those calculated in the burden of disease studies as a technical input, instead of the total of the priorities obtained separately from morbidity and mortality.

Priorities need to be set based on comprehensive methodologies rather than on morbidity or mortality alone.

Contributing to the determination of health priorities

The results obtained from the burden of disease study are an essential input when combined with the other elements that have an influence on the determination
of health priorities such as cost, effectiveness of interventions, equity and policy options.

The resource limitation makes it necessary for us to prioritize in order to make an investment aimed at generating effective healthcare benefits, thus bringing benefits to the largest possible population. Consequently, investments based on burden of disease priorities will be more cost-effective than those based on either mortality or morbidity alone.

9 Mathers CD, Sadana R, Salomon JA, Murray CJ, Lopez AD. Healthy life expectancy in 191 countries, 1999. Lancet 2001; 357: 1685-91.

10 Polinder S, Haagsma JA, Stein C, Havelaar AH. Systematic review of general burden of disease studies using disability-adjusted life years. Popul Health Metr. 2012; 10: 21.

Indirect Advantages

Improvement in the quality and coverage of information systems. An additional effect achieved when developing burden-of-disease studies is that morbidity and mortality data can be used together to assess the strengths and weaknesses of information systems. Therefore, it will guide the recommendations for their improvement in terms of coverage and data quality.

This will all be possible as each country develops its own burden of disease study. Failure to do so, and only waiting and relying on international estimates (passively data use) means that the possibility of impacting on the improvement of information systems will be lower.

Active versus passive use of data

A good practice in public health is the use of data in program management and decision making, and it is far better if used actively. The active use of data leads to a close involvement in the production of the data, thus closing the cycle of - Information - Analysis and use - Identification of information needs - Strategies for improvement - Information. The passive use of data involves only waiting for the data to become available for the purpose of analysis.

Cycle of continuous improvement of data use

The greater the use of data, the greater the probability of identifying problems and therefore improving information systems. Corrections must be planned in the short term (gradual solutions) and in the long term (investment in human and technological resources)

Other indirect advantages[11,12]

- Design action plans aimed at identifying vulnerable population groups
- Better manage health programs
- Establish health investments
- Establish research priorities
- Help determine public health interventions
- Estimate the demographic impact of different interventions
- Contribute to cost effectiveness evaluations. The results of the burden of disease, together with information on costs, will allow the evaluation of the effectiveness of health interventions and the analysis of the equity-related impacts of their implementation.

In conclusion, since burden of disease studies have a synthetic and unified indicator, which brings together fatal and non-fatal outcomes, they better describe the health status of a population. It will therefore allow for good decision making, especially in those situations where it is necessary to look at the data in a unified way, thereby helping to better establish health priorities.

Legal Frameworks

11 Murray CJL, Lauer JA, Hutubessy RCW, Niessen L, Tomijima N, Rodgers A, et al. Effectiveness and costs of interventions to lower systolic blood pressure and cholesterol: a global and regional analysis on reduction of cardiovasculardisease risk. Lancet. 2003; 361: 717–25.

12 N. Fernández de Larrea-Baz et al. Años de vida ajustados por discapacidad perdidos por cardiopatía isquémica en España. Rev Esp Cardiol. 2015; 68 (11): 968–975

Burden of disease studies should not be merely declaratory and should be confined only to the field of Epidemiology, Statistics or some technical unit in the Ministries or Secretariats of Health. On the contrary, they should go beyond these internal borders and extend their reach to the other areas of government and civil society.

In this sense, it is not enough to develop technical approaches through forums and discussions, but it is necessary to establish closer connections between the technical and political aspects. Basically, a link between the various regulatory documents in force in the country (whether Ministerial Resolutions, Supreme Decrees, Laws, etc.) should be reviewed to serve as a bridge and link it to the objectives of the burden of disease. If it is possible, create specific regulations, and the more distant from the technical institution involved, the better. For example, it is appropriate if the regulation is endorsed by the Ministry or Secretariat of Health, but it would be better if it is endorsed by the entire office of the Council of Ministers and even better if it is signed by the Legislative Branch (be it the Congress of the Republic, the Chamber of Deputies, the Senate, etc.).

These strategies will make the burden of disease study process more sustainable over time. Examples that support the above are the Universal Insurance Law in Peru[13]or the law that establishes the General System to Guarantee Healthcare in Chile [14], or specifically the Mental Healthcare Law[15], where the burden of disease studies are expressly and declaratively indicated as inputs to the design and monitoring of these policies.

13 Perú, Congreso de la República. Ley N°29344: Ley marco de aseguramiento universal de salud. Lima: Congreso de la República; 2009.

14 La Ley Nº 19.966: Régimen General de Garantías en Salud. Chile 2004.

15 Perú, Congreso de la República. Ley N° 30947: Ley de Salud Mental. Lima: Congreso de la República; 2019.

III METHODOLOGICAL ASPECTS

The burden of disease is a methodology that measures the health status of a population. The burden of disease is measured by a synthetic indicator called Disability-Adjusted Life Year, which stands for DALY.

Disability-free Healthy Life Years (HLY): These are the years of life that a person enjoys in good health without having a disability.

Disability-adjusted Life Year (DALY): This is the synthetic indicator that assesses the burden of disease at the population level, providing joint information on the fatal and non-fatal consequences of diseases, injuries, and risk factors[16]. It is expressed in units of time (years), therefore a DALY is a lost year of healthy life. The DALY is calculated as the sum of two indicators, the years of life lost (YLL) and the years lived with a disability (YLD), which are explained below.

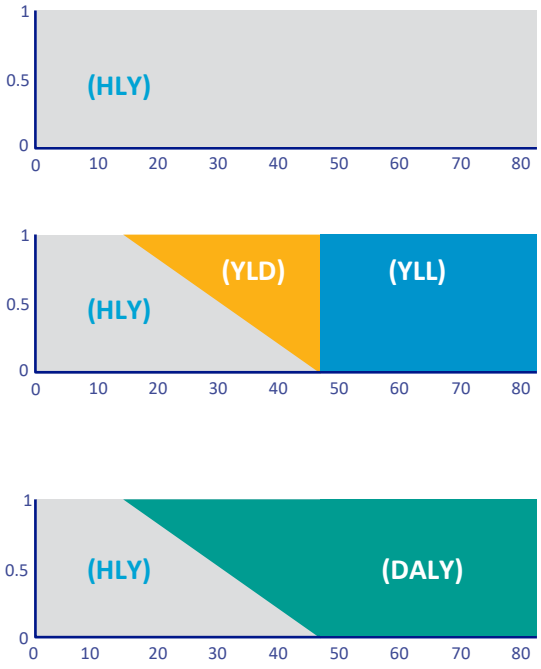


Figure 1
The burden of disease measures the loss of healthy years of life (disability-free) as a result of death, illness or injury:

DALY = YLL + YLD

Years of lost life (YLL): It is an indicator that evaluates mortality status (the fatal outcomes of health status) and represents the length of time lost between the age of death of each deceased and an arbitrary age limit. For the YLL calculation, it is necessary

16 Murray CJL, Lopez AD. The global burden of disease. A comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990 and projected to 2010. Boston (MA): Harvard University Press; 1996. p. 1–118.

to know the number of deaths for each cause of death and the age when the death occurred. The age limit used is the standard life expectancy for each age, which is determined from a low-risk mortality population based on the lowest age-specific mortality rates recorded in the countries.[17, 18]

YLL = Number of deaths x (life expectancy at age of death - age of death)

Years lived with a disability (YLD): This is an indicator that evaluates the state of morbidity (the non-fatal outcomes of health status) and represents the length of time lost as a result of suffering from a disease and/or its sequelae. For the YLD calculation, it is required to know the:

- disease incidence (number of new cases),
- duration of disability caused by the disease,
- age of onset of disease and
- the degree of disability it causes.

In recent studies of burden of disease, there have been changes in the initial methodology described in the 1993 publication, especially in the parameters referred to social assessments (discount options and weighting by age). Thus, in the first study a discount rate of 3% was used and age was weighted, determining a greater emphasis on young adult health outcomes.

The following updates by the World Health Organization (WHO) for the years 1999, 2000, 2001, 2002 and 2004 also considered these social values. However, from the 2010 Global Burden of Disease (GBD) study onwards, which was the result of extensive consultation, the discount rate and age weighting were no longer used. Therefore, at present YLDs are based on the prevalence product of a sequela and its associated disability weight.[19, 20]

The following is a brief description of the parameters used in the calculation of the YLDs.

YLD = Number of new cases x Age of onset x Duration x Disability weight

Disability weight

The disability weight shows the severity of the illness on a scale of 0 (perfect health) to 1 (death), with intermediate values according to the different classes of disability. These values also allow to establish equivalences with the YLLs, so that both measures (YLL and YLD) are comparable.

It should be noted that the results of the 2010 GBD study disability weights were based on judgments about the severity of health obtained through surveys applied to the general public, in contrast to the 1990 GBD which was based on judgments of health professionals.

17 GBD 2017 DALYs and HALE Collaborators. Global, regional, and national disability-adjusted life-years (DALYs) for 359 diseases and injuries and healthy life expectancy (HALE) for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. Lancet 2018; 392: 1859–922

18 Murray CJL, Ezzati M, Flaxman AD, et al. The Global Burden of Disease Study 2010: design, definitions, and metrics. Lancet 2012; 380: 2063–66

19 Murray CJL, Ezzati M, Flaxman AD, et al. The Global Burden of Disease Study 2010: design, definitions, and metrics. Lancet 2012; 380: 2063-66.

20 Lopez AD, Mathers CD, Ezzati M, Jamison DT, Murray CJ, eds. Global burden of disease and risk factors. Washington, DC: Oxford University Press and The World Bank, 2006

Although it could be thought that the sequel to an illness, its severity and its disability would be different according to the age, sex, and origin of the patient and that it could change over time, there is evidence that disability weights do not substantially change between origin, socioeconomic level, or educational level [21,22]. Therefore, the disability weights used in burden of disease studies come from the 2010 GBD study available at the Institute for Health Metrics and Evaluation [23] (IHME) website (http://ghdx.healthdata.org/ gbd-2017).

Duration of disability

It is the average time, expressed in years, that a disability lasts as a result of an injury, illness or sequel. The time is counted from the time the disability appeared until it remitted (either by permanent cure or as a result of death). There are estimates already calculated for each condition according to age groups and sex, which are available at the IHME website (http://ghdx.healthdata.org/gbd-2017).

Age of onset of disability

It is the average age, expressed in years, in which the disability appears as a result of an injury, illness or sequel, according to knowledge of natural history and epidemiology. There are estimates already calculated for each condition according to age groups and sex, which are available at the IHME website (http://ghdx.healthdata.org/gbd-2017).

Disease incidence

To estimate the YLD, it is necessary to know the number of new cases for each of the diseases. As with the other parameters mentioned, this information should be broken down by age group and sex. There are also estimates already calculated for each country; however (as shown below) the necessary adjustments must be made to obtain information that is closer to the country's epidemiological situation.

21 Salomon JA, Vos T, Hogan DR, et al. Common values in assessing health outcomes from disease and injury: disability weights measurement study for the Global Burden of Disease Study 2010. Lancet2012; 380: 2129-43.

22 Salomon JA, Haagsma JA, Davis A, et al. Disability weights for the Global Burden of Disease 2013 study. Lancet Glob Health2015; 3: e712–23.

23 It is an independent global health research center at the University of Washington.

IV GLOBAL ESTIMATES AND ADJUSTMENT WITH LOCAL DATA

The IHME's published estimates for the various countries are made using an indirect method [24], since it mostly uses mortality and incidence data from each of the countries. As expected, not all countries have measurements for all diseases, nor do they all have the same level of quality and coverage of health data.

Therefore, when the GBD takes the best available data and after certain and complex processes, it obtains information for each of the diseases according to a standard list and classifies them according to different geographical areas of the world. Thus, those countries sharing the same geographical area will have the same parameters and inputs for the burden of disease. Although this aspect has increasingly been improved, as the estimate
for more geographical areas has been increased and thus heterogeneity among countries has decreased, there is still some dissatisfaction with the data estimated for some countries [25]. These differences highlight the importance of using national and local epidemiological data to obtain more accurate estimates for each country.

It is necessary to know the process that IHME uses to obtain health information from the countries in order to explain the importance of adjusting the estimates from the GBD study to the local reality of each country. Although the data used in the GBD studies are based on official data sent by each country to international agencies. After submission, each country uses internal processes to adjust its data, matching its own official sources
and published data may differ from the data initially submitted to international agencies. This can be seen by looking at the gaps between the year of publishing and the year of the information sources used in the countries' official publications. Therefore, recent changes in official data for each country (after submission or collection by global health agencies), could not be recorded in the GBD studies.

An additional consideration is that there are very rigorous criteria in the GBD for the admission of sources from each country, which follow Guidelines for Accurate and Transparent Health Estimates Reporting [26] (GATHER). It has its advantages and disadvantages. On the one hand, having the best possible evidence is good, especially if a study of a global magnitude such as the GBD is to be done, where countries are compared on a timely basis and over time, that is, there is a lot of specificity in the selection of studies. However, this leaves out

24 Murray CJL, Lopez AD. The global burden of disease. A comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990 and projected to 2010. Boston (MA): Harvard University Press; 1996. p. 1–118.

25 Eurostat. Health statistics – Atlas on mortality in the European Union. 2009 edition, Luxembourg: Office for Official Publications of the European Communities; 2009. p. 117–8

26 Stevens GA, Alkema L, Black RE, et al. Guidelines for accurate and transparent health estimates reporting: the GATHER statement. PLoS Med2016; 13:e1002056

a lot of information that is produced locally in each country (management information systems) and also some local publications that disseminate data on prevalent diseases specific to the country, which may not have international scope because they are not in indexed or high-impact journals. Therefore, it must be wider to collect more local information (be as sensitive as possible), evaluate, discriminate and keep the best information possible.

The above has been acknowledged within the limitations of the 2017 GDB study, which focuses primarily on delays or absence of data submissions and recent changes in measurement by countries - determining that some useful information is not captured in the overall estimates. [27]

It should be made explicit that **an uncertain estimate** - even when data are scarce or **unavailable - is considered preferable to having no estimate** at all, since a lack of estimates can usually be interpreted as no health loss from that condition.

Disadvantages of analysis focused on international estimates

i) They do not show the limitations of local information systems

ii) They depend on external updating deadlines

iii) It is impossible to obtain or break down data according to local needs

27 GBD 2017 DALYs and HALE Collaborators. Global, regional, and national disability-adjusted life-years (DALYs) for 359 diseases and injuries and healthy life expectancy (HALE) for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. Lancet 2018; 392: 1859–922

V SELECTION OF DISEASE LIST

For the burden of disease study, it is important to define how the various causes of DALYs will be organized and presented. Therefore, the first element to be agreed upon by the teams of the Ministries or Secretariats of Health is which classification list they will use.

GBD studies have proposed a standard classification based on epidemiological criteria organized at various hierarchical levels. Thus, in the GBD 2017 study, the list includes 359 causes of DALYs, with 282 causes of death and 354 causes of non-fatal health losses, distributed in 4 levels of hierarchy that are described in the table below.

Table 1. Classification of causes according to level

Level 1	Level 2	Level 3	Level 4
Large groups of causes: Communicable diseases, maternity, neonatal and nutritional diseases. Non-communicable diseases. Injuries.	22 causes	169 causes	293 causes

At each level the causes are mutually exclusive and collectively exhaustive [28, 29]

It is recommended that the general structure of the above-mentioned list be maintained and that it be disaggregated or aggregated to a greater or lesser extent depending on the epidemiological profile of each country. Therefore, the number of diseases included in a national list will differ according to their particular characteristics.

The advantage of the GBD list is that there is detailed information for each of the 359 causes of DALY, including data on all the parameters necessary for the estimation of the YLDs (incidence, age of onset, duration and disability weight) and the YLLs (number and death rate). However, it is necessary to pay attention to the " remnants " of the diseases, which appear in the list with the names of (the remnants of the..., the rest of...., the other...). This is because when the burden of disease is analyzed globally as in the case of GBD studies,

28 GBD 2017 Cause of Death Collaborators. Global, regional, and national age-sex-specific mortality for 282 causes of death in 195 countries and territories, 1980–2017: a systematic analysis for the Global Burden of Disease Study 2017. Lancet 2018; 392: 1736-88.

29 GBD 2017 Disease and Injury Incidence and Prevalence Collaborators. Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017:a systematic analysis for the Global Burden of Disease Study 2017. Lancet 2018; 392: 1789–858

the residual causes are the least frequent. However, when the unit of analysis is reduced to a national or sub-national study, the least frequent cause for the world could be the most frequent and even an important cause. It is, therefore, necessary to remove them from these "remnant" groups and raise them to a higher level.

In conclusion, it is recommended that each country should select the list that best fits its own epidemiological situation, based on the description of the list provided by the GBD.

The third and fourth level of disaggregation can be modified according to the frequency and importance of the different pathologies in the populations studied.

It is necessary for **each country to establish the list** it will use for its burden-of-disease study and to understand that its results will not be comparable to the GBD estimates.

VI NECESSARY INFORMATION FOR THE BURDEN OF DISEASE STUDY

As mentioned above, the burden of disease indicators is built from mortality and morbidity information. It is also known that there has been a global collaborative effort to obtain statistical and epidemiological information in order to develop and report consistent estimates of DALY (including each of its components and parameters) for each of the countries and make them available (at IHME website) in a comprehensive and disaggregated manner by disease list according to age groups and sex.

Whether or not to replace the estimated data published in the GBD study?

The data that could be completely or partially replaced by local data are those corresponding to the number of deaths and disease incidence figures. The other parameters referring to the age of onset of the disability, average duration and disability weight should not be modified.

The decision to replace it or not will depend on the prior assessment of the soundness of the data from the country's information systems. For this purpose, the team should analyze each of the data that the GBD estimates for its country and determine whether or not that estimate is consistent with the epidemiological situation.

It is important to remember that the replacement of data is followed by a whole internal modeling process in order to have a more consistent result with adequate internal validity. For this step, it is relevant to note that there are software programs, such as DisMod [30], that facilitates this process by supplementing missing data and forcing consistency among the data that were available.

Therefore, from the data set required to develop a burden of disease study, there is a group that will not need to be estimated and adjusted with national data (Non-modifiable data); while others will (Modifiable data).

Non-Modifiable Data
(from the IHME)

- Disability weight
- Age of onset of a disease
- Duration of disability

Modifiable Data
(to be adjusted with national data)

- Disease incidence
- Number of Deaths

30 https://www.who.int/healthinfo/global_burden_disease/tools_software/en/

Sources of information for the adjustable data (incidence and deaths)

Disease incidence

The data on the incidence of diseases is necessary for the building of the YLD indicator. Although there is information already estimated for each country (http://ghdx.healthdata.org/gbd-2017), it is essential to review it and compare it with national data to make the necessary adjustments in order to have information that is closer to the country's epidemiological situation.

Because of this, and after the country has defined the list of diseases for the study of each disease, the next step is to evaluate if solid national data are available to estimate the necessary parameters that support the calculation of the YLD. To this end, a detailed and systematic review of all possible sources should be carried out for each cause of disease defined in the classification list determined by the country.

i. Government Sources

Sources that come from the official records of the Ministries or Secretariats of Health. They are collected routinely, continuously, and permanently and with high levels of disaggregation by age groups and sex. They give us information on the distribution patterns of diseases.

- Annual morbidity reports: In many countries, each year, the statistics or epidemiology offices of the Ministries or Secretariats of Health report a summary of the main causes of morbidity by origin: outpatient care, hospital discharges, or emergencies. Although these data do not provide specific information on whether they are incidental or prevalent, they do guide us on how the diseases are distributed among the various age and sex groups at the national and sub-national levels.
- Epidemiological Surveillance Systems: Epidemiology offices provide continuous and timely information on diseases subject to mandatory notification. It is important to take into account the case definitions used in each country in order to know whether it is prevalence or incidence.
- Cancer records: Sometimes, there are official records for certain diseases such as cancer, which are mainly carried out in reference hospitals and detail the information for the various specific types of cancer.

ii. Population-based sources

Sources from planned studies that are not routinely collected by government agencies or universities. They are necessary to adjust the data obtained by the government sources.

- Research studies on the prevalence of certain diseases: In several countries, surveys are conducted for diseases such as malnutrition in children under five, HIV-AIDS, diabetes, and high blood pressure, among others. Some are done on a regular basis, others occasionally.

- Domestic journals: There are scientific journals in the countries, indexed or not, where published studies on the incidence or prevalence of communicable or non-communicable diseases can be found.
- Thesis Repositories: There is a wide scientific output at the undergraduate and graduate levels in several university centers in the country. Some are available in web repositories and are easily accessible.

Number of Deaths

The death data are important inputs for the calculation of the YLL indicator. Similarly, to the data on disease incidence, in the case of deaths, there is also information already estimated for each country (http://ghdx.healthdata.org/gbd-2017); however, it is necessary to review it and compare it with the national data to make the corresponding adjustments.

The main source of mortality data is a vital statistics system. This system depends on some countries on the Ministries or Secretariats of Health; in other cases, it depends on the Civil Registries, and in others, it is a hybrid with certain shared functions. In any case, it is necessary to note that although death is an unequivocal event and is recorded by the statistics systems of many countries, it is still a problem in terms of quality and coverage.

i. Mortality databases from vital events systems: It provides information on the registry of the number of deaths by specific cause and age groups. In recent years many countries have made efforts to strengthen vital information systems in terms of quality and coverage. However, countries must perform certain additional procedures, to a greater or lesser extent, to improve the quality of death certification and correct underreporting.
   While the source for mortality is the vital events system, other sources to correct underreporting are required, such as Demographic and Health Surveys, censuses, and population estimates by the Institutes of Statistics.
ii. Population censuses: Some population censuses allow for the estimation of general mortality indicators, necessary for the correction of underreporting of deaths.
iii. Demographic and Family Health Surveys: These are surveys conducted periodically to estimate child, newborn, and maternal mortality.

The organization of the health system and official information systems

Information systems will be based on the way health systems and services are organized. That is, if the health system is unified, data will flow in one direction to respond to this system. In a
fragmented system, data will be organized according to the requirements of each subsystem, making integration more difficult. Another consideration is whether the country is centralized or decentralized, and whether its political-administrative division is independent or responds to a central government. This will influence the flow and consolidation of data to higher levels, creating advantages or disadvantages in the timeliness of the data.

For each cause of disease, epidemiological estimates of morbidity parameters must be made.

It is required:

- To have a deep understanding of the epidemiology of each cause of disease
- To know the characteristics of the information systems for each cause of disease: availability, completeness, internal consistency, level of disaggregation.
- Available tools for data processing and output.
- Technical capacity of human resources

Strategies for finding sources of information

Step 1. Searching for information sources

It is necessary to establish an effective search that guarantees as many sources of information as possible. To this end, open space should be promoted to convene the different governmental or academic subject experts, who will suggest potential sources of information when asked.

- Searching in official sources
  Often one has the impression that they know all the official health information systems and believe that they are all in the Ministry or Secretariat of Health. However, ad hoc studies or registries of valuable importance for the study of the burden of disease may exist in other government ministries or institutes. Therefore, a comprehensive review and extension of the search scope should be undertaken to identify as many sources of information with national and local coverage as possible.
- Searching in unofficial sources
  Intensive health data search strategies need to be established so that as much information as possible is covered. Be as sensitive as possible and then have a more exhaustive criterion to discern what is most convenient (be more specific). Have open criteria and not just limit it to indexed journals or to information accessible on the Internet. It should be taken into account that there is unpublished information stored in university library repositories, scientific societies that can be very useful.

  It is recommended to do an inventory of the possible sources of information to establish an order or method to classify the information obtained, recording if it is incidence or prevalence data, of national or subnational inference, of disaggregation by sex and age groups, and its frequency of update.

Steps to search for information

1. Identification and call for experts according to topic
2. Request for Proposals
3. List of sources to check: differentiate official and unofficial sources
4. Search and inventory of sources
5. Evaluation, Classification and Selection of sources
6. Result record

Step 2. Evaluation of information sources

Official or unofficial information systems must be evaluated in terms of quality and coverage. There are various forms of evaluation, either qualitative or quantitative, and there are even guidelines for this [31].

Each country must make a diagnosis and evaluation from the quantitative and qualitative standpoint within its own information systems, both generally and specifically (for each disease) in terms of data quality and coverage. This is important because it will allow you to know the advantages and limitations of the system.

31 Stevens GA, Alkema L, Black RE, et al. Guidelines for accurate and transparent health estimates reporting: the GATHER statement. PLoS Med2016; 13:e1002056

Figure 2
Procedures for estimating YLDs

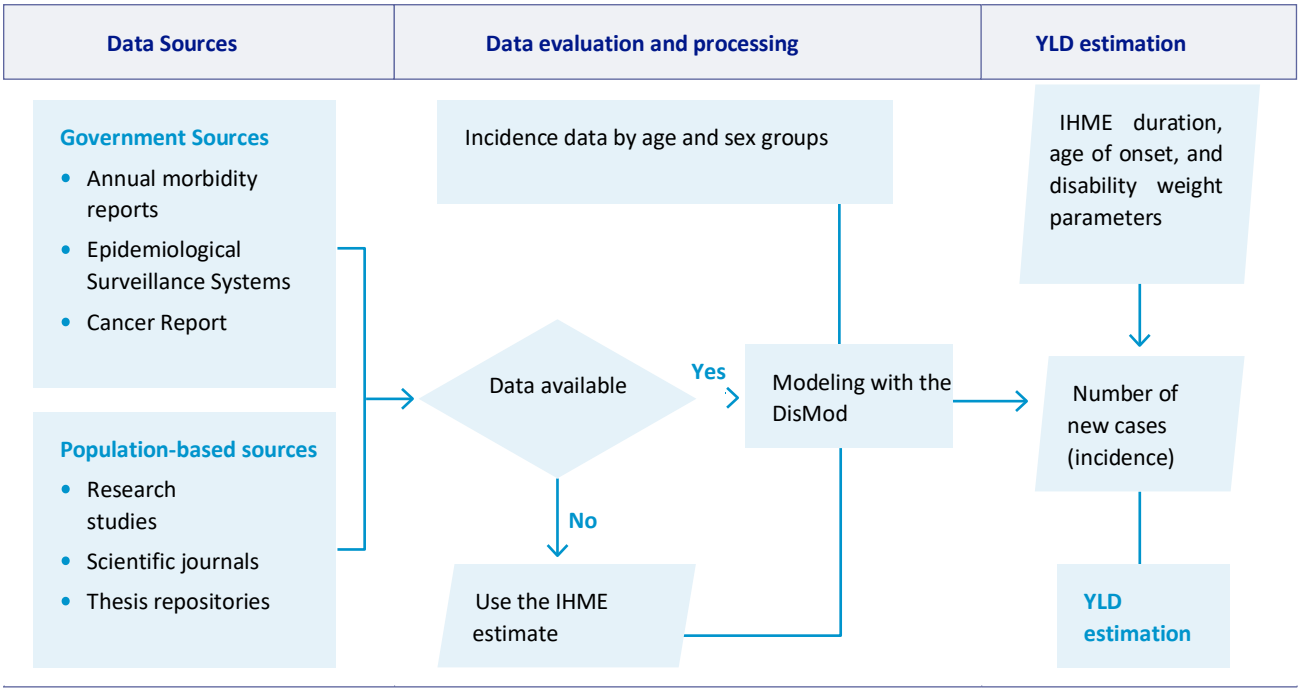
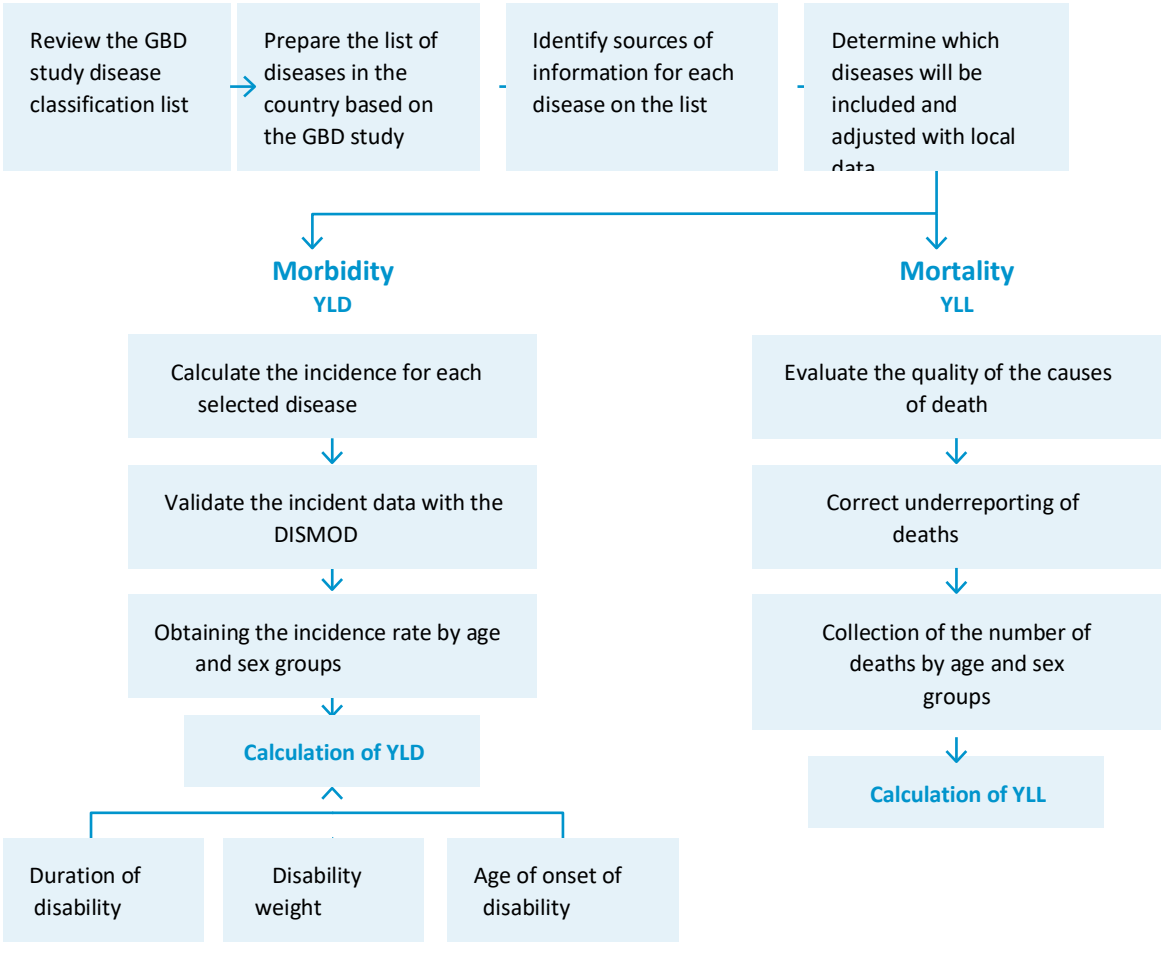


Figure 3
Steps for calculating YLD and YLL indicators



Data from the IHME

VII PRESENTATION AND USE OF RESULTS

An important point after the completion of an epidemiological study and especially a burden of disease study is the publication of the report, the presentation, and dissemination of its results. Therefore, the steps involved must be clearly established.

In the first place, the first publication of a standard type should be considered, aimed at a very heterogeneous public that, even though it is not very specialized, provides a general and technical overview and invites the reader to identify issues of interest and advocacy issues. Secondly, the presentation should be as broad and formal as possible, but at the same time, it should be highly directed to those groups that have an impact on health decision-making, including the media. At this point, it is important to create a common agenda with the communications and press departments of the Ministry or Secretariat of Health. Finally, in addition to a printed edition, an easily accessible electronic version should be made available to ensure adequate coverage and dissemination on social networks.

A second step is the planning of the responses that would be triggered after the report is known. They range from very specific inquiries to invitations to take part in technical round tables. It is important to have a list of key decision-makers and potential stakeholder meetings that may arise, and therefore nothing is left out of the list.

This planning goes from understanding the particular interest of the decision-makers to designing the strategy to effectively influence the results of the study. It is necessary to prepare an ad hoc executive summary to be handed out to the participants. This report should be as clear and easy to understand as possible in order to contribute to making good decisions.

Remember that each presentation space should be considered an opportunity to deliver a key message that will be the trigger for promoting the use of the data and that this data will be the basis for creating a health policy.

Considerations for the meeting:

- Be prepared for the meeting
- Get to know the meeting participants and identify the role play between them
- Know in advance the context where the meeting will take place
- Be clear about the purpose of the meeting:
  - **Informative:** raising awareness
  - **Methodological:** specifying some kind of specific result
  - **Technical:** as an input to give a greater added value to the result. For example, estimate the cost-effectiveness of an intervention.
  - **Political:** Contributing to the support of public policy and decision making
- Learn what the decision-maker wants and be clear about what you want to convey and persuade.
- Prepare a report and presentation according to the objective of the meeting.

Considerations for preparing a report:

- Identify the target audience
- Establish the purpose of the report
- Prepare a brief summary with key messages
- Use a quick and easy to understand writing style
- Identify whether the information to be displayed will be general and informative or specific, more technical and focused.
- Know how to use the report:
  - **Informative**
  - **Technical:** Input to perform additional procedures. For example, estimate the cost-effectiveness of an intervention.
  - **Political:** Input to support the design of a public policy

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DATA FOR HEALTH INITIATIVE

Vital Strategies