

Second meeting of the Burden of Disease Manual Working Group of the European Burden of Disease Network (EBoDN)

Berlin, Germany
21 August 2018



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Burden of Disease
Manual Working Group of the
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ABSTRACT

The second meeting of the Burden of Disease (BoD) Manual Working Group of the European Burden of Disease Network was convened, like the first meeting, by the WHO Regional Office for Europe, with the Institute for Health Metrics and Evaluation (IHME), and cohosted by the Robert Koch Institute in Berlin, Germany on 21 August 2018. The working group was formed by the Network to finalize work on the BoD manual.

The goal of the BoD manual is to describe the resources and methods necessary to perform a BoD study that produces internationally comparable results while acknowledging that different countries have different needs and that data availability differs widely.

IHME was given the task of revising and finalizing the current version of the BoD manual in accordance with suggestions made by the working group, with the aim of having it completed by late 2018.

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Abbreviations

BoD burden of disease

GATHER Guidelines for Accurate and Transparent Health Estimates Reporting

GBD Global Burden of Disease

IHME Institute for Health Metrics and Evaluation

Executive summary

In May 2015, WHO and the Institute for Health Metrics and Evaluation (IHME) signed a memorandum of understanding on collaboration to improve burden of disease estimation and utilization in decision-making. The memorandum included a commitment that WHO and IHME would work together to develop a national burden of disease (BoD) manual. The first draft of the manual was completed in August 2016.

In August 2018, the third meeting of the European Burden of Disease Network was convened by the WHO Regional Office for Europe, jointly with IHME, and hosted by the Robert Koch Institute in Berlin, Germany. The goal of this meeting, like the previous ones, was to increase the capacity of Member States in the WHO European Region to perform BoD studies using harmonized methods, primarily with a view to increasing the comparability of studies across countries. The Network aims to address the needs of countries that are interested in BoD studies, with the goal of applying comparable and internationally accepted methods. The Network is contributing to the preparation of the BoD manual through the BoD Manual Working Group.

The second meeting of the Working Group took place on 21 August 2018 in Berlin, Germany. It was convened by the WHO Regional Office for Europe, jointly with IHME, and cohosted by the Robert Koch Institute. The meeting fully achieved its objectives of:

- discussing the proposed content of the BoD manual;
- reaching agreement on the next steps for finalizing the manual.

The goal of the BoD manual is to provide an update of the 2001 WHO publication *National burden of disease studies: a practical guide*, taking account of recent developments in BoD methodologies. The manual should offer guidance on ways of undertaking a BoD study, with an emphasis on regional and global harmonization, either by making use of the Global Burden of Disease (GBD) studies conducted by IHME or by proceeding independently, or both.

According to the agreement reached at the previous meeting in 2017, a revised draft of the manual was shared by IHME with members of the group prior to the second meeting of the Working Group. The Working Group discussed the draft and identified and presented several final suggestions for additions and revisions.

IHME will distribute a revised draft of the manual to the working group by October 2018, to be shared with WHO headquarters and finalized by late 2018.

Introduction

The second meeting of the Burden of Disease (BoD) Manual Working Group of the European Burden of Disease Network took place in Berlin, Germany on 21 August 2018. The meeting was convened by the WHO Regional Office for Europe, jointly with the Institute for Health Metrics and Evaluation (IHME), and cohosted by the Robert Koch Institute (for the programme of work, see Annex 1; for the revised terms of reference of the Working Group, see Annex 2). The diverse group of meeting participants included epidemiologists, BoD principal investigators, academics and representatives of national health institutes involved in BoD studies, or who plan to start a BoD study (for the list of participants, see Annex 3).

Participants were welcomed to the meeting by Dr Claudia Stein (Director, Division of Information, Evidence, Research and Innovation, WHO Regional Office for Europe) and Professor Peter Allebeck (Professor/Senior Physician, Department of Public Health Sciences, Karolinska Institutet, Sweden), who chaired the meeting.

Dr Aline Anton (Robert Koch Institute) was elected as rapporteur. Participants were invited to declare any conflicts of interest; none were declared. The programme was adopted.

Objectives of the meeting

The aims of the second meeting of the BoD Manual Working Group were to discuss the content of the revised draft BoD manual, and to define and agree on the next steps for the finalization of the document. The expected outcomes included the following:

- agreed final version of the BoD manual
- agreement on the next steps for the finalization of the manual.

Background

The European Burden of Disease Network was established by the WHO Regional Office for Europe following a recommendation from the European Health Information Initiative Steering Group in 2016. Its aim is to increase the capacity of Member States in the WHO European Region to perform burden of disease (BoD) studies using harmonized methods, primarily with a view to increasing the comparability of studies across countries. The Network aims to address the needs of countries that are interested in BoD studies, with the aim of applying comparable and valid methods. IHME, which is the coordinating institution for the Global Burden of Diseases, Injuries, and Risk Factors Study, is a joint convener of the Network and will contribute to activities and efforts to support the advancement of BoD capacity in the WHO European Region.

To this end, IHME and WHO are developing a manual with guidance on conducting national BoD studies (the BoD manual), to which the Network is contributing through a dedicated working group. The first meeting of the working group took place in Oslo, Norway on 22 August 2017, convened by the Regional Office, jointly with IHME, and cohosted by the Norwegian Institute of Public Health. IHME was given the task of revising the current version of the BoD manual following the suggestions made by the working group, with the aim of finalizing the manual by late 2018.

Current status of the manual

The IHME representative, Ms Meghan Mooney, described the background and current status of the manual. The following is a summary of her presentation.

Goals of the manual

- To update the 2001 WHO publication *National burden of disease studies: a practical guide*.
- To offer guidance on the conduct of a BoD study with an emphasis on regional and global harmonization, either by making use of the GBD study or by proceeding independently, or both.
- To outline the pros and cons of each approach and the key decisions to be made along the way.
- To point the reader to existing BoD resources and provide a concise guide that does not replicate these resources unnecessarily.
- To lay out practical considerations relevant to scientific, technical and managerial issues.
- To identify special considerations relevant to the conduct of subnational studies.

Contents of the manual

- Section 1 – key components of BoD studies: purpose, principles, measures, value.
- Section 2 – conducting a national BoD study, summary information: team capacity, timeline, infrastructure, training, access to data sources.
- Section 3 – conducting a national BoD study: data sources, extraction and harmonization; analysis, interpretation, achieving impact.
- Section 4 – analytical components: detailed summary of analytical components, including methods, flowcharts and code links; computation of summary measures.
- Section 5 – special considerations for subnational BoD: data sources, geographical hierarchies, covariates.
- Section 6 – resources and opportunities: GBD resources, including collaborative network, training opportunities, publications, web-based tools, code and data library (Global Health Data Exchange).

The first draft of the BoD manual was based on work undertaken at IHME to make BoD studies compliant with the Guidelines for Accurate and Transparent Health Estimates Reporting (GATHER); it included detailed methods, descriptions, analytical code and complete lists of data sources. As with all GBD publications, the manual should be GATHER-compliant, which will ensure the transparency of studies based on the manual.

Discussion

The participants warmly welcomed the enormous progress made since the last version of the manual, and commended IHME. In addition, IHME and the working group participants remarked that it is important to outline the benefits of a national BoD approach and to supplement the section on policy impact with outcomes, targets and timelines. It is important to emphasize the advantages for countries in terms of acceptance of results, especially for health policy. Also, prevalence, incidence and utilization indicators should be presented in relation to demographic indicators. Again, the different levels of collaboration between IHME and countries was part of the discussion, with a focus on how to start a national BoD study and the use of training opportunities provided by IHME.

Arguments for working closely with IHME include the smaller team of experts needed because of the close collaboration involved and the training opportunities provided for close collaborators. The use of international, standardized methods can help to resolve data gaps

and provide easier access to methodological solutions. In summary, this type of cooperation ensures high quality and comparability of studies.

Arguments for performing more independent studies included the following: it may be necessary to adhere strictly to a specified schedule when collaborating with IHME and, although it may be very appealing for policy-makers if collaboration with IHME means that fewer staff members are needed, outsourcing capacities to IHME can pose problems of funding and data protection. Moreover, local ownership of data and methods can be very important to local policy-makers, overriding the need for comparability; however, advantages include transparency of statistical modelling and a greater degree of flexibility when testing various assumptions inherent in the models used.

Nevertheless, WHO representatives emphasized that international comparability is key for international reporting of national BoD studies. For this reason, if countries choose to perform stand-alone BoD studies independently of the IHME infrastructure, it would always be desirable to use a combination of both approaches to ensure local applicability as well as international comparability.

The following points were raised as possible additions/revisions to the draft manual.

1. A definition of a BoD study should be added in the preamble to the manual; explanations of basic measures, such as the disability-adjusted life-year and years of life lost, are essential for comparability, along with definitions of metrics, measures and indicators.
2. The standard life expectancy should stay the same within a country, but the possibility of using the country's own estimates for local policy should be discussed.
3. The structure of the manual should be revised; the description of the different levels of involvement should be moved to one chapter; the case study section should be moved to Chapter 5 and Chapters 5 and 6 should be changed. A text on standardization and cleaning of data should be added.
4. It was suggested that the mediation section needs clarification and a step-by-step description, with examples; the key goals for risk factors should be included and a link to theoretical minimum risk exposure levels should be given.
5. A paragraph on bias and uncertainty correction should be added; covariates should be explained in more detail and in relation to subnational studies; a list of covariates should be added to the annex.
6. The sequela list remains to be added.
7. The term "garbage codes" should be replaced by other terms, such as "inappropriate", "uninformative" or "less informative", which are also valid codes.
8. The need for a person trained in demography should be added to the competence description for BoD teams; information on the minimum number of staff members needed should be added, depending on the level of cooperation with IHME.
9. A short section on policy impact could be added. Although it is part of the WHO remit to work with Member States on the translation of evidence into policy, advantages for countries should be made clearer.
10. Flow charts will be more effective if the links are shown at a high resolution.
11. More detail should be provided about the way the estimates are calculated; greater transparency would be helpful, especially for visualization tools.

12. Training possibilities should be mentioned, since the manual is not replacing training, but providing orientation.

13. A chapter on future directions and forecasting could be included.

The working group suggested that the language of the manual should be made clearer – it should be simple and easy to read. The manual should acknowledge examples of national BoD studies (e.g. in Scotland and the Netherlands) and the strong and positive connection with the European Burden of Disease Network. The role of identifying own data sources could be outlined in hybrid approaches using various degrees of collaboration between countries and IHME.

Next steps

The working group made detailed recommendations to IHME about the revisions. IHME agreed to give feedback on the extent to which the action items could be integrated into a new draft of the manual.

IHME will distribute a revised version of the manual to the working group by October 2018, which will be shared with WHO headquarters. The manual is scheduled for finalization by end of 2018.

Annex 1. Programme of work

Tuesday 21 August 2018

Welcome and opening remarks

Professor John Newton, Chair of the Network, Professor Peter Allebeck, Professor/Senior Physician, Department of Public Health Sciences, Karolinska Institutet, Chair of the BoD Manual Working Group, and Dr Claudia Stein, WHO Regional Office for Europe

Introduction of participants

Election of rapporteur

WHO Secretariat

Adoption of the agenda and programme

Chair

Presentation on the status of the BoD manual

IHME

Discussion of, and agreement on, the content of the BoD manual by chapter

IHME, all

Discussion of, and agreement on, the content of the BoD manual by chapter (continued)

IHME, all

Agreement on next steps and on the elements for the presentation to the Network the following day

All

Any other business

Closing remarks

Chair, WHO Secretariat

Annex 2. Revised terms of reference

Terms of reference **of** the Burden of Disease Manual Working Group **of the European Burden of Disease Network**

Aim of the working group

To discuss and contribute to the Institute for Health Metrics and Evaluation (IHME)'s development of a national BoD manual and related methodologies for conducting national BoD studies that ensure international comparability. The working group will operate under the auspices of the EBoDN.

Tasks

The working group will:

- discuss the scope, aims and requirements of the national BoD manual
- review and agree on methodologies for national BoD studies
- report to the EBoDN and seek its feedback
- establish a workplan for the working group and agree on timelines.

Main outputs

The main outputs will be:

- meeting reports documenting progress, and a workplan
- the finalized national BoD manual, including related guidance and support tools.

Chair

The working group will appoint a Chair to coordinate the work of the group and to facilitate a free exchange of views and information among group members (and with the EBoDN). The Chair will be elected on a rotational basis.

Meetings

The group will convene as mutually agreed between members. Additional meetings may be called when required and if funding permits; otherwise, the work can be complemented by virtual meetings (via email exchange and tele- or videoconference). The dates and the mode of meetings (physical or electronic), as well as agendas, will be determined by the Chair of the working group in consultation with the WHO Secretariat, bearing in mind available resources.

Composition of the working group/membership

Members of the working group are appointed through the EBoDN and include experts with relevant subject-matter knowledge and experience to provide important technical advice. Members of the group are expected to attend the working group meetings; to participate in telephone conferences and interactions via email; and to review and provide timely feedback on documents produced by the working group (such as meeting reports).

21 August 2018

Annex 3. List of participants

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The WHO Regional Office for Europe

The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health. The WHO Regional Office for Europe is one of six regional offices throughout the world, each with its own programme geared to the particular health conditions of the countries it serves.

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