

First meeting of the Burden of Disease (BoD) Manual Working Group of the European Burden of Disease Network

Oslo, Norway
22 August 2017





**World Health
Organization**

REGIONAL OFFICE FOR **Europe**

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ABSTRACT

The first meeting of the European Burden of Disease Network (EBoDN)'s Burden of Disease (BoD) Manual Working Group was convened by the WHO Regional Office for Europe jointly with the Institute for Health Metrics and Evaluation (IHME) and co-hosted by the Norwegian Institute of Public Health on 22 August 2017 in Oslo, Norway. The working group was formed by the EBoDN to finalize work on the BoD manual.

The goal of the BoD manual is to describe the staff and methods necessary to perform a valid 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 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
EBoDN	European Burden of Disease Network
GATHER	Guidelines for Accurate and Transparent Health Estimates Reporting
GBD	global burden of disease
IHME	Institute for Health Metrics and Evaluation
WHO	World Health Organization

Executive summary

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

In September 2016, the first meeting of the European Burden of Disease Network (EBoDN) was convened by the WHO Regional Office for Europe jointly with IHME and co-hosted by Public Health England in London, United Kingdom. The goal of establishing this network was rooted in increasing 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 EBoDN aims to address the needs of countries that are interested in BoD studies with the goal of applying comparable and valid methods. The EBoDN is contributing to the BoD manual through a dedicated working group.

The first meeting of the EBoDN's BoD Manual Working Group was convened by the WHO Regional Office for Europe jointly with IHME and co-hosted by the Norwegian Institute of Public Health on 22 August 2017 in Oslo, Norway. The meeting fully achieved its objectives of:

- reaching agreement on the terms of reference for the BoD Manual Working Group;
- reaching agreement on the next steps for developing the BoD manual.

The goals of the BoD manual are to provide an update of the 2001 WHO publication *National burden of disease studies: a practical guide*, taking account of recent developments in BoD science. The manual should offer guidance on how to undertake a BoD study with an emphasis on regional and global harmonization, either by making use of the global burden of disease (GBD) study or by proceeding independently, or both.

A draft of the manual was shared by IHME with members of the group prior to the first meeting of the BoD Manual Working Group on 22 August 2017. The draft was discussed, and several suggestions for additions and revisions were identified and presented by the working group.

IHME will distribute a revised draft of the manual to the working group by December 2017, and the next meeting will take place in early 2018 to finalize the manual.

Introduction

The first meeting of the European Burden of Disease Network (EBoDN)'s Burden of Disease (BoD) Manual Working Group was convened by the World Health Organization (WHO) Regional Office for Europe jointly with the Institute for Health Metrics and Evaluation (IHME) and co-hosted by the Norwegian Institute of Public Health on 22 August 2017 in Oslo, Norway (see Annex 1 for the programme). The diverse group of meeting participants included epidemiologists, BoD principal investigators, academics, and representatives of national health institutes involved in BoD studies (see Annex 3 for the list of participants).

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 was elected as Chair of the meeting.

Ms Heidi Lyshol (Norwegian Institute of Public Health) 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 first meeting of the BoD Manual Working Group were to agree on the terms of reference for the working group, to discuss the content of the draft BoD manual, and to define and agree the next steps for further development. The expected outcomes included:

1. agreement on the terms of reference for the working group;
2. agreement on the next steps for developing the BoD manual;
3. a report summarizing the discussions held, conclusions reached, and action points agreed at the meeting.

Background

In May 2015, WHO and IHME signed a memorandum of understanding to collaborate together to improve BoD estimation and utilization in decision-making. The memorandum established that WHO and IHME together would develop a manual of BoD best practices. In June 2016, WHO, IHME and other global experts adopted GATHER (Guidelines for Accurate and Transparent Health Estimates Reporting) – a set of guidelines on standards of transparency and replicability in health research. To make the global burden of disease (GBD) study fully GATHER-compliant, IHME began publishing all methods, computational code and data sources for the Global Burden of Disease Study 2015 (GBD 2015); this material provided the foundation for the BoD manual. The first draft was completed in August 2016.

In September 2016, the first meeting of the EBoDN was convened by the WHO Regional Office for Europe jointly with IHME and co-hosted by Public Health England in London, United Kingdom. The goal of establishing this network 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 WHO Regional Office for Europe performed a literature review to identify all relevant BoD studies published in the Region since 1997 (paper now in press with the *European journal of public health*). The EBoDN aims to address the needs of countries that are interested in BoD studies with the goal of applying comparable and valid methods. The EBoDN is contributing to the BoD manual through the work of a dedicated working group.

Present status of the BoD manual

IHME representative Ms Meghan Mooney presented the background and present status of the BoD manual. The following is a summary of her presentation.

Goals of the manual

- Providing an update of the 2001 WHO publication *National burden of disease studies: a practical guide*.
- Offering guidance on how to undertake 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.
- Outlining the pros and cons of each approach and the key decisions to be made along the way.
- Pointing the reader to existing BoD resources and providing a concise guidebook that does not replicate these resources unnecessarily.
- Laying out practical considerations relevant to scientific, technical and managerial issues.
- Identifying special considerations relevant to conducting 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 – Analytic components: detailed summary of analytic 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 GATHER-compliant; it included detailed methods, descriptions, analytic code, and complete lists of data sources. The first draft was completed in August 2016 and reviewed by WHO. The second draft had been completed by September 2016, in time for presentation at the first meeting of the EBoDN. The third draft was completed and shared in July 2017, and a fourth draft was shared prior to the first meeting of the BoD Manual Working Group on 22 August 2017.

Discussion of contents of the BoD manual

IHME explained that it welcomed national BoD studies being performed in collaboration with IHME and using IHME infrastructure. Two working group participants remarked that this approach could be problematic with regard to acceptance of results in their respective countries. A discussion followed of the pros and cons of either working closely with IHME or conducting national BoD studies independently.

Arguments for performing independent studies included: a potentially higher degree of acceptance of results among local authorities and national stakeholders; local ownership of data and methods; transparency of statistical modelling; and a greater degree of flexibility with respect to testing various assumptions inherent in models. In addition, this approach would foster national capacity-building, be sensitive to local needs, and perhaps have greater success in attracting funding.

Arguments for working closely with IHME included: the fact that IHME had already found solutions for many of the pitfalls newcomers to BoD might encounter; use of international, standardized methods to resolve data gap problems; the danger that BoD studies performed outside the IHME framework might suffer from compromised quality and lack of comparability; and the advantage that working with IHME would mean that the data provided would help inform global estimates.

WHO representatives underlined that international comparability was compromised with use of non-comparable BoD methods. For this reason, agreement on a common set of methods, as described in the manual, was important. There might be many valid reasons why countries would choose to perform stand-alone BoD studies independently of the IHME infrastructure. Nevertheless, even in such cases, adherence to the methods described in the BoD manual would still be required in order to ensure international comparability.

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

1. Decision-making processes at IHME could be explained.
2. Context and overview of BoD and explanations of basic measures, such as disability-adjusted life years (DALYs) and years of life lost (YLL), could be added, along with definitions of metrics, measures and indicators.
3. Possibilities for simplification, such as presenting a less comprehensive cause list, could be discussed.
4. Details of how evidence reviews are performed at IHME could be given.
5. Discussion of (systematic) evidence reviews, incorporating WHO standards, could be included.
6. Sequela list and health states could be added.
7. Description of garbage codes and redistribution process, including possibility of software for distribution, could be given.
8. Competence description of BoD team should be revised, adding minimum requirements (in terms of persons/years) to carry out a stand-alone/collaborative national study: 3–5 persons/3–5 years are indicated by examples from the Netherlands, Sweden and the United Kingdom (England and Scotland).
9. Information could be given on how to start BoD work on a small scale, expanding to meet needs and in line with resources.
10. A list of different tools for BoD reporting at country level could be added.

The working group suggested that the tone of the manual should be made more neutral and value-free, avoiding promotion of any particular institution or structure. The manual should acknowledge other

paths to conducting a national BoD study (as seen, for example, in Scotland and the Netherlands). Moreover, hybrid approaches using various degrees of collaboration between countries and IHME could be outlined.

Next steps

The terms of reference for the BoD Manual Working Group were discussed and approved with minor changes (Annex 2).

The working group made detailed recommendations for revision to IHME.

IMHE will distribute a revised version of the manual to the working group by December 2017. The next meeting will take place in early 2018 to finalize the manual.

Annex 1. Programme

Tuesday 22 August 2017

Welcome and opening remarks

Professor John Newton, Chair of the EBoDN, and Dr Claudia Stein, WHO Regional Office for Europe

Introduction of participants

Selection of the Chair, rapporteur, and spokesperson of the BoD Manual Working Group for the presentation at the EBoDN meeting

WHO Secretariat

Adoption of the agenda and programme

Chair

Discussion and agreement on the terms of reference

Chair, all

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

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

Definition of, and agreement on, next steps of the working group

All

Agreement on the elements for presentation to the EBoDN meeting on the following day

All

Closing remarks

Chair

Annex 2. Revised terms of reference

Terms of reference for the Burden of Disease (BoD) Manual Working Group within the European Burden of Disease Network (EBoDN)

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 work plan for the working group and agree on timelines.

Main outputs

The main outputs will be:

- meeting reports documenting progress, and a work plan;
- 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 between 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).

22 August 2017

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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