First meeting of the European Burden of Disease Network (EBoDN)

London, United Kingdom
20–21 September 2016

World Health Organization

REGIONAL OFFICE FOR Europe

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Abstract

The first meeting of the European Burden of Disease Network (EBoDN) was convened by the WHO Regional Office for Europe jointly with the Institute for Health Metrics and Evaluation (IHME) and co-hosted by Public Health England on 20–21 September 2016 in London, United Kingdom. The EBoDN was born out of recommendations from the European Health Information Initiative (EHII) Steering Group in spring 2016. The goal of establishing this network is rooted in increasing 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 IHME, which is the coordinating institution for the Global Burden of Diseases, Injuries, and Risk Factors Study, is joint convener of the EBoDN and will contribute to activities and efforts to support the advancement of BoD capacity in the European Region. As an important first step, IHME and WHO will develop a national BoD manual, in which the EBoDN will contribute towards its scope and content. The vision, mission and aims of the network were formulated, and a series of activities were agreed upon for the upcoming year in a work plan.

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Contents

Abbreviations

BoD	burden of disease
DALY	disability-adjusted life year
EBoDN	European Burden of Disease Network
EHII	European Health Information Initiative
GATHER	Guidelines for Accurate and Transparent Health Estimates Reporting
GBD	global burden of disease
IHME	Institute for Health Metrics and Evaluation
MOU	memorandum of understanding
WHO	World Health Organization
YLD	years lived with disability
YLL	years of life lost

Executive summary

Burden of disease (BoD) is a method of measuring the impact of disease by combining measures of mortality, morbidity and disability. It is extremely useful to illustrate the relative magnitude of different health concerns, and provides a strong framework for prioritization in health policy. However, current studies are poorly harmonized, with considerable methodological variations. This presents a key challenge in the validation of results, their comparability across countries, and understanding at a regional level.

To address concerns of comparability and to increase the practice and use of BoD studies, the World Health Organization (WHO) Regional Office for Europe launched the European Burden of Disease Network (EBoDN) on 20–21 September 2016 in London, United Kingdom, jointly with the Institute for Health Metrics and Evaluation (IHME) and co-hosted by Public Health England.

The first meeting of the network brought together principal investigators and representatives of national BoD studies to discuss the BoD landscape across the European Region and to define the scope and activities of the network. The IHME is a joint convener of the EBoDN and will contribute to activities and efforts to support the advancement of BoD capacity in the European Region. The network will primarily act in a strategic and leadership function, but will draw upon the significant technical expertise of its members.

The first meeting fully achieved its objectives of:

- formally launching the network;
- defining and agreeing upon the network's scope and purpose, terms of reference, modus operandi, and roles of network members; and
- formulating a work plan of actions, milestone tasks, and responsibilities.

As an important first step, IHME and WHO will develop a national BoD manual to aid countries in performing local BoD studies in a harmonized manner. The EBoDN will contribute towards the formulation of the manual. The proceedings of the meeting are summarized in this report.

Network members emphasized the importance of and value in BoD studies through the EBoDN Manifesto:

Mindful of resolution EUR/RC66/R12 – *European action plan to strengthen the use of evidence, information and research for policy-making in the WHO European Region – we, the members of the EBoDN, request the WHO Regional Office for Europe to:*

- *continue to support the European Health Information Initiative (EHII) as a fundamental basis for international comparisons in population health status;*
- *ensure a close collaboration with Member States and the IHME, in the area of BoD;*
- *support the building of sustainable capacity, structures and resources in BoD methods in Member States and the conducting of BoD studies;*
- *encourage Member States to use BoD evidence for decision-making;*
- *advocate for the EBoDN to increase its membership; and*
- *encourage similar initiatives in other WHO Regions.*

Introduction

The first meeting of the EBoDN was convened by the WHO Regional Office for Europe on 20–21 September 2016 in London, United Kingdom (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 2 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), Professor John Newton (Chief Knowledge Officer, Public Health England) who was elected as Chair of the meeting, and Dr Mohsen Naghavi (Professor of Global Health, IHME).

Mr Omid Fekri was elected as rapporteur. Participants were invited to declare any conflicts of interest; none were noted. The programme was adopted.

Objectives of the meeting

The first meeting of the EBoDN was intended to enhance collaboration among a diverse group of countries with similar aims, and to enable effective knowledge exchange between experts in the field of BoD studies. The expected outcomes of the first meeting were:

1. the formal launch of the EBoDN in the WHO European Region;
2. agreement on the EBoDN’s scope and purpose, terms of reference, modus operandi, and the roles of network members;
3. the formulation of a Work Plan (including actions, milestone tasks, and responsibilities); and
4. a summary report of discussions, conclusions reached, and action points agreed for the network.

Work of WHO on the global burden of disease (GBD)

BoD is a method of measuring disease impact by combining measures of mortality, morbidity and disability. As one of its main summary measures, it uses disability-adjusted life years (DALY). This measure is very useful for illustrating the relative magnitude of different health concerns (specific diseases or risk factors), and provides a strong, valid framework for prioritization in health policy-making. Despite the value of good BoD research, current studies across the Region are poorly harmonized, with considerable variations in disability weights, discounting, and age-weighting, as well as whether incidence or prevalence measures are used in years lived with disability (YLD) calculations, regularity of YLD updates, and concerns regarding missing/unclear data. This presents a key challenge in the validation and comparability of results, their comparability across countries, and understanding at a regional level.

Beginning with the first published GBD study in 1993, WHO has collaborated with national and international partners in the advancement of standards and classification methods, gathering of data, and calculation of estimates on morbidity, disability and mortality. Since that time, there have been numerous updates at WHO and more detailed analyses, including annual revisions, publications on risk factors, and cost–effectiveness analyses. In 2001, WHO published a toolkit and manual for national or subnational assessments on BoD *(1)*. In recent years, the IHME has taken on a global role of estimating the GBD, with current projects providing comprehensive assessments for 195 countries and territories and over 300 diseases and conditions *(2,3)*.

As a result of strong interest among WHO European Member States in conducting BoD studies at the national level, the Steering Group of the EHII emphasized the need for harmonizing and standardizing the BoD approach across the European Region, and at their annual meeting in March 2016 requested that the WHO Regional Office for Europe set up the EBoDN *(4)*.

The EHII provides an overarching framework for health information activities for the WHO European Region within six key areas (see Box 1). It was launched with the vision of implementing a single health information system for the European Region, and strives to strengthen the health information that underpins policy-making in the Region. There are currently 26 partners within the EHII, including Member States, WHO collaborating centres, national institutions, and organizations such as the European Commission, the Organisation for Economic Cooperation and Development (OECD), the Wellcome Trust, and the Commonwealth.

The EBoDN is the fourth such network within the EHII, following the Central Asian Republics Health Information Network (CARINFONET), the Small Countries Health Information Network (SCHIN), and the Evidence-informed Policy Network (EVIPNet).

Box 1. EHII six key areas

EHII works in six key areas:

1. gathering and analysing information that deepens the understanding of health and well-being, with a focus on indicators;
2. enhancing access to and dissemination of health information;
3. building capacity;
4. strengthening health information networks;
5. supporting the development of health information strategies; and
6. communication and advocacy.

Overview of published national studies of the BoD in Europe

In preparation for the launch of the EBoDN, the WHO Secretariat, through Mr Mark O'Donovan, undertook a detailed literature search to understand better the landscape of national BoD studies in the European Region, the results of which he then presented to the group. This review was the first review of its kind known for the European Region. Since 1997, a total of 170 national BoD studies using the DALY metric have been published in the English language by principal investigators, on study populations within the WHO European Region (see Table 1).

The distribution of studies progressively grew from one in 1997 to 22 in 2015. Studies were located for 21 out of the 53 Member States in the European Region, with the greatest number of studies from the Netherlands (64 studies), then Spain (18 studies), Belgium and the United Kingdom (13 studies each), and Denmark and Portugal (10 studies each); the remaining 15 Member States conducted five or fewer studies. Thirty-two Member States appear never to have conducted their own BoD study. The majority of studies (91 out of 170) looked at a specific disease, condition or topic, and 24 of these were multicountry studies. There were 13 full BoD studies assessing the complete suite of diseases and conditions at the national level, including two with subnational divisions. Nine full BoD studies only investigated subnational situations.

The findings show diverse practices and methodologies used by countries, and therefore supports the need for a harmonized approach in BoD methodology. Furthermore, this analysis indicates where nationally generated BoD estimates are currently unavailable.

This review will enhance the visibility and publication of BoD studies.

Table 1. Number and type of BoD studies in the WHO European Region since 1997 (by country, in order of total number of studies conducted)

Study type	Netherlands	Spain	Belgium	United Kingdom	Denmark	Portugal	France	Germany	Sweden	Italy	Poland	Serbia	Estonia	Switzerland	Austria	Bulgaria	Albania	Lithuania	Norway	Romania	Turkey
Full national (subnational divisions)	-	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-	1
Full national	-	5	-	-	-	-	1	-	2	-	-	1	1	-	-	-	-	-	-	1	-
Full subnational	-	2	1	3	-	1	1	-	-	-	-	-	-	1	-	-	-	-	-	-	-
Multiple diseases or conditions	21	2	2	3	1	1	-	1	-	-	1	1	-	-	-	-	-	-	-	-	-
Specific disease or condition	34	8	8	5	9	8	1	3	2	3	1	2	1	-	2	2	1	-	1	-	-
Multicountry (attribution to the Member State of the principal investigator)	9	1	2	2	-	-	2	1	1	1	2	-	-	2	-	-	-	1	-	-	-
Total	64	18	13	13	10	10	5	5	5	4	4	4	3	3	2	2	1	1	1	1	1

Work of the IHME on the GBD

The IHME at the University of Washington in Seattle, United States of America, is an independent global health research organization that provides rigorous and comparable BoD assessments to determine the world's most important health problems, and evaluates the strategies used to address them. The IHME's mission is to improve health through better health evidence *(5)*.

The IHME defines the GBD project as a systematic scientific effort to quantify the comparative magnitude of health loss due to disease, injury and risk factors by age, sex, and geography for specific points in time. Since the release of GBD 2010, the IHME has served as the global GBD coordinating centre and currently has over 1 900 collaborators across 125 countries. It has authored over 700 research publications related to GBD since 2007. The GBD project produces comprehensive, comparable national estimates of BoD for 195 countries and a growing number of countries at the subnational level.

In 2015, WHO and the IHME signed a Memorandum of Understanding (MOU) with the aim of collaborating more closely in the area of BoD, thus improving the data used to generate estimates of levels and trends in health. A key deliverable of this MOU is the production of an instructional manual for countries to undertake national and subnational BoD assessments. This new manual will build on and replace the earlier toolkit published by WHO in 2001 *(1)*. It is anticipated that the manual will be released in 2017 with the members of the EBoDN contributing to its scope and content.

The IHME is a major supporter of the Guidelines for Accurate and Transparent Health Estimates Reporting (GATHER) *(6)* published in 2016. GATHER contains detailed requirements for scientific studies to increase the understanding and transparency of results, methodology, software code, and metadata used in modelling for estimates. GBD 2015 is GATHER-compliant.

National BoD studies in Europe

Meeting participants provided updates on BoD studies from their respective institutions (covering Belgium, Denmark, Germany, the Netherlands, Norway, the Russian Federation, Serbia, Sweden, Switzerland and the United Kingdom (England and Scotland)). It was evident from the 11 presentations that there is a substantial amount of BoD work underway in the European Region. The purposes and scope of these activities are diverse, ranging from full national BoD studies in England, Scotland and Norway to more specific analyses on, for example, foodborne diseases in Denmark. Some countries and institutes have established strong collaborations with the IHME to produce nation-specific reports and tools on BoD results, such as the Norwegian *Findings from the Global Burden of Disease* report *(7)*, and the *GBD Compare Public Health England* tool *(8)*. There is also strong heterogeneity across countries in the availability of data sources, with some countries using detailed disease-specific registries and comprehensive primary data, while other countries need to rely on estimates from secondary data sources.

Understandably, the findings of these respective BoD studies are not entirely comparable as they serve local purposes and use varying methodologies and datasets. If, however, there were methodologies and platforms to allow disparate national BoD studies to be performed in a manner that would allow some degree of true comparability, there would be a benefit to Member States and researchers within the European Region in not only raising the capacity of BoD analyses, but also identifying common health areas of concern that might require intersectoral or regional action. EBoDN members concurred that the dual approach of carrying out local studies fit for purpose, but with the highest achievable comparability to other BoD studies, would be the optimal approach.

Challenges in and opportunities for harmonizing BoD methods in the WHO European Region

Researchers from the Federal Research Institute for Health Organization and Informatics, Ministry of Health of the Russian Federation, examined a subset of 56 BoD studies from 16 countries identified through the WHO Secretariat's review of the WHO European Region. The purpose of this assessment was to identify common challenges in and differences between BoD studies, and to identify opportunities for harmonization of methodologies for more comparable findings. Each BoD study was reviewed on the following criteria: the application and methodology of BoD estimates, types of data sources utilized, the geographical level analysed, and the scope of diseases under study.

There was a high level of consistency across the studies in applying the calculation methodology for DALY using YLD and years of life lost (YLL) (DALY = YLD + YLL), with nine studies from three countries that focused on environmental BoD utilizing a different computational DALY definition[1]. There was a notable degree of variability in the data sources used by countries, ranging from national statistics, WHO estimates, disease registries, insurance systems, or data from other studies. As a result, the comparability of studies across countries and their international value was limited since the data sources used varied in completeness, coverage, and depth.

There was similar variability in the sets of diseases assessed within the BoD studies; about one-third of studies used the standard set of GBD study diseases, followed by customized sets, infections, foodborne diseases, cancers, and injuries. There is justification for this variation as it is often determined by the availability of data, the particular researcher's area of focus, use of a specific programme toolkit, or relevance to a country's needs.

A majority of countries performed analyses and reported results at the national level. There were twice as many regional studies (using data from only one region or city of the country) than subnational studies (using regional and national data to calculate subnational results).

Overall, the review identified methodological variation across respective national BoD studies. These variations call for and can be addressed by harmonizing BoD methodology so that future studies across countries can be compared in valid and meaningful ways. The EBoDN can provide a platform for evaluation and consideration of different components of BoD methodology.

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[1] The environmental DALY = AB*D*S, where AB is attribution burden, D is duration of health state, S is severity of health state. Source: Knol AB, Staatsen BAM. Trends in the environmental burden of disease in the Netherlands 1980–2020. Bilthoven: RIVM; 2005.

Benefits of harmonized BoD methodologies: proposal for a new practical guide

The MOU between the IHME and WHO to improve cooperation on BoD methodology, data sharing and estimates and to increase Member State capacity in performing BoD studies included the key step of developing the *Practical guide to national BoD studies* manual. The IHME is currently assembling a working group to develop the draft manual, and welcomed the involvement of experts from the EBoDN. The IHME and WHO will co-host working meetings in early 2017 to finalize the manual.

EBoDN members showed great interest in the proposed manual, and confirmed its usefulness to increase local capacity in performing national and subnational BoD studies. The manual will be appropriately detailed and comprehensive to address all aspects of BoD analyses. A key item under discussion was the focus of the manual, and whether it would be developed in a manner that would aid local, nation-specific BoD analyses that did not allow for comparability with other countries, or methodological processes that would ensure the resultant estimates would be consistent and comparable across countries and studies.

Network members strongly favoured a hybrid approach to the manual that allowed for national specificity while maintaining international comparability. The manual could be drafted in a way that followed standard BoD methodology to perform national/subnational studies, but then arrived at a cut-off point in which any further customization of the methodology to a local context would deviate from comparability with other countries, with the potential to document the differences to the harmonized methodology. This hybrid model would meet the requirements of both types of study, and provide local adaptation fit for the precise scope of the BoD study, while at the same time setting localized studies into a defined relationship to the global BoD context.

The vision, mission, and aims of the EBoDN and next steps

The EBoDN is principally a strategic group of experts that will advise and inform the advancement of BoD analyses in the WHO European Region. These leadership functions will include developing new partnerships with European Region Member States and with the IHME to expand knowledge on BoD (including identification of new data sources, and BoD practitioners); dialogue with policy-makers on the importance and appropriate use of BoD analyses; planning for European Region BoD projects; aligning the work of the EBoDN with the EHII; and advocating for long-term sustainability of BoD analyses at the national level.

In addition, the EBoDN will serve as a technical group providing BoD methodological expertise. These contributions include proposing new causes of death to be included in GBD projects; advising on methodological enhancements to BoD studies, including complementary methods such as descriptive epidemiology; providing technical assistance in the uptake of new data sources to IHME's GBD calculations; participating in the working group informing the new BoD manual; contributing to software tool development; and overall, providing a peer-review function on networking and BoD activities in general.

The aforementioned activities and functions discussed over the two-day meeting informed the agreement on the network's vision, mission and aims (see Annex 3 for the network's Terms of Reference). A work plan of concrete actions and deliverables was produced, outlining responsibilities and timelines for the upcoming year (see Annex 4 for the complete EBoDN Work Plan 2016–2017). Table 2 summarizes the main action points discussed during the meeting.

Table 2. Summary of main action points

Action	By when
Strategic activities	
• Establish working group for finalization of the national BoD manual	Q4 2016
• Identify networks and groups working on BoD	Q4 2016
• Promote access to data used in BoD (through review of IHME reports on data revisions)	Q1 2017
• Outreach for new members to the network	Q1 2017
• Advocate for long-term sustainability of BoD analyses and appropriate use of results in practice	Q1 2017
• Identify opportunities for BoD training	Q2 2017
Technical activities	
• Contribute to the development of the national BoD manual	Q1 2017
• Identify, promote and share experiences of BoD studies	Q1 2017
• Identify and promote information on international and national BoD activities (through a dedicated EBoDN website)	Q1 2017
• Provide methodological expertise to the GBD study	Ongoing

To emphasize the importance of this work, members of the EBoDN agreed on a manifesto outlining necessary actions for the WHO Regional Office for Europe to take in order to attain the vision, mission and aims of the network (see Box 2). The EBoDN anchors itself within the EHII and the recently adopted WHO Regional Committee for Europe resolution EUR/RC66/R12 on a European action plan to strengthen the use of evidence, information and research for policy-making to fulfil the goals of the Health 2020 policy framework.

Network members unanimously elected Professor John Newton, Chief Knowledge Officer, Public Health England, as Chair of the EBoDN, and Dr Henk Hilderink, Senior Scientific Researcher, National Institute for Public Health and the Environment (RIVM), the Netherlands, as Deputy-Chair, both for an initial two-year term. The EBoDN will convene a virtual meeting in six month's time, and the next in-person meeting will take place in Oslo, Norway in August 2017. A special working group composed of EBoDN members will meet early 2017 to develop further the BoD manual.

Box 2. EBoDN Manifesto

Mindful of resolution EUR/RC66/R12 – European action plan to strengthen the use of evidence, information and research for policy-making in the WHO European Region – we, the members of the EBoDN, request the WHO

Regional Office for Europe to:

- continue to support the EHII as a fundamental basis for international comparisons in population health status;
- ensure a close collaboration with Member States and the IHME, in the area of BoD;
- support the building of sustainable capacity, structures and resources in BoD methods in Member States and the conducting of BoD studies;
- encourage Member States to use BoD evidence for decision-making;
- advocate for the EBoDN to increase its membership; and
- encourage similar initiatives in other WHO Regions.

The participants of the first EBoDN meeting © WHO/Olga Fradkina

Conclusions

The first meeting of the EBoDN brought together principal investigators and representatives of national BoD studies with the aim of increasing analytical capacity across countries and enhancing the comparability of results across the European Region.

The IHME is a key member of the EBoDN and will contribute to activities and efforts to support the advancement of BoD capacity in the European Region. As an important first step, the IHME and WHO will develop a national BoD manual to aid countries in performing local BoD studies. The EBoDN will convene a working group in early 2017 to provide input and suggestions for the content of the manual.

The EBoDN was formally launched with agreed terms of reference and scheduled activities for the upcoming year. The network will primarily act in a strategic and leadership function, but will draw upon the significant technical expertise of its members. The EBoDN will hold a virtual meeting in about six months' time, and the next in-person meeting will take place in Oslo, Norway in August 2017.

References

1. Mathers CD, Vos T, Lopez AD, Salomon J, Ezzati M, editors. National burden of disease studies: a practical guide. Edition 2.0. Global Program on Evidence for Health Policy. Geneva: World Health Organization; 2001 (http://www.who.int/healthinfo/nationalburdenofdiseasemanual.pdf, accessed 7 November 2016).

2. Wang H, Murray CJL, Lopez A, Vos T, Naghavi M, Allen C, et al. Global, regional, and national life expectancy, all-cause mortality, and cause-specific mortality for 249 causes of death, 1980–2015: a systematic analysis for the Global Burden of Disease Study 2015. Lancet 2016;388:1459–1544. doi: 10.1016/S0140-6736(16)31012-1.

3. Kassebaum NJ, Arora M, Barber RM, Bhutta ZA, Brown J, Carter A, et al. Global, regional, and national disability-adjusted life-years (DALYs) for 315 diseases and injuries and healthy life expectancy (HALE), 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015. Lancet 2016;388:1603–58. doi: 10.1016/S0140-6736(16)31460-X.

4. European Health Information Initiative: fourth meeting of the Steering Group. Copenhagen: WHO Regional Office for Europe; 2016 (http://www.euro.who.int/__data/assets/pdf_file/0019/321562/Report-4th-meeting-EHII-Steering-Group-en.pdf, accessed 7 November 2016).

5. Institute for Health Metrics and Evaluation and World Health Organization sign new agreement. In: IHME [website]. Seattle, WA: IHME; 2015 (http://www.healthdata.org/announcement/institute-health-metrics-and-evaluation-and-world-health-organization-sign-new, accessed 7 November 2016).

6. GATHER Statement. In: GATHER [website]. Geneva: WHO; 2016 (http://gather-statement.org/gather-statement/, accessed 9 December 2016).

7. IHME. Norway: state of the nation’s health. Findings from the Global Burden of Disease. Seattle, WA: IHME, 2016 (http://www.healthdata.org/sites/default/files/files/policy_report/2016/PolicyReport_IHME_GBD-Norway_2016.pdf, accessed 9 December 2016).

8. GBD compare – Public Health England | Viz. In: IHME [website]. Seattle: IHME; 2016 (https://vizhub.healthdata.org/gbd-compare/england/, accessed 7 November 2016).

Annex 1. Programme

<u>Tuesday, 20 September 2016</u>

Welcome and opening remarks

- Professor John Newton (Chief Knowledge Officer, Public Health England)
- Dr Claudia Stein (Director, Division of Information, Evidence, Research and Innovation, the WHO Regional Office for Europe)
- Dr Mohsen Naghavi (Professor, Institute for Health Metrics and Evaluation)

Introduction of participants

Nomination of Chairperson and Rapporteur (proposal by WHO Secretariat)

Adoption of the provisional agenda and provisional programme (Chairperson)

Work of the WHO Regional Office for Europe on the global burden of disease (Dr Claudia Stein)

Objectives of the meeting and expected outcomes (Dr Christian Gapp)

Work of IHME on the global BoD (Dr Mohsen Naghavi)

Discussion

Harmonization of methods for measuring the BoD in Europe (Dr Claudia Stein)

Overview of published national studies of the BoD in Europe (Mr Mark O'Donovan)

Discussion

Update on planned, continuing or unpublished national BoD studies (Principal investigators)

Challenges in and opportunities for harmonizing BoD methods in Europe – *quo vadis*? (Dr Yekaterina Nosova)

Discussion

Benefits of harmonized BoD methodologies: proposal for a new *Practical guide to national BoD studies* (Dr Mohsen Naghavi and Ms Meghan Mooney)

Discussion

Reflections from day 1 (Chairperson, WHO Secretariat, IHME)

<u>Wednesday, 21 September 2016</u>

Summary of key points outlined in day 1 and expectations for day 2 (Chairperson)

The European Burden of Disease Network in the context of the European Health Information Initiative (EHII) (Dr Claudia Stein)

Discussion and agreement on the vision, mission and aims of the EBoDN (Chairperson)

- Discussion and agreement on the Terms of Reference of the EBoDN
- Discussion and agreement on next steps – drafting the EBoDN work plan
- Agreement on frequency and dates of next meetings

Closing remarks (Chairperson)

Annex 2. List of participants

Ms Emilie Agardh
Assistant professor
Department of Public Health Sciences
Karolinska Institutet, Sweden
Email: Emilie.agardh@ki.se

Professor Peter Allebeck
Professor/senior physician
Department of Public Health Sciences
Karolinska Institutet, Sweden
Email: Peter.allebeck@ki.se

Dr Brecht Devleesschauwer
Epidemiologist
Scientific Institute of Public Health, Belgium
Email: brecht.devleesschauwer@wiv-isp.be

Mr Omid Fekri (Rapporteur)
Independent consultant
Toronto, Canada
Email: omid.fekri@utoronto.ca

Dr Julian Flowers
Public Health England, United Kingdom
Email: Julian.Flowers@phe.gov.uk

Dr Thomas Fürst
Postdoctoral Scientific Collaborator
Department of Epidemiology and Public Health
Swiss Tropical and Public Health Institute, Switzerland
Email: Thomas.Fuerst@unibas.ch

Dr Ian Grant
Principal Researcher
Scottish Burden of Disease Study
The Scottish Public Health Observatory, United Kingdom
Email: ian.grant@nhs.net

Dr Henk Hilderink
Senior Scientific Researcher
National Institute for Public Health and the Environment (RIVM)
The Netherlands
Email: Henk.Hilderink@rivm.nl

Professor Dr Milena Šantrić Milićević
Institute of Social Medicine
University of Belgrade Facaulty of Medicine, Serbia
Email: msantric@med.bg.ac.rs

Ms Meghan Mooney
Senior Engagement Manager
Institute for Health Metrics and Evaluation
United States of America
Email: megham2@uw.edu

Professor Mohsen Naghavi
Professor of Global Health
Institute for Health Metrics and Evaluation
United States of America
Email: nagham@uw.edu

Professor John Newton
Chief Knowledge Officer
Public Health England, United Kingdom
Email: John.Newton@phe.gov.uk

Dr Yekaterina Nosova (via videoconference)
Lead Researcher
Department of Mathematical Modelling in
Public Health
Federal Research Institute for Health Organization and Informatics of the Ministry of Health
Russian Federation
Email: cnosova@gmail.com

Mr Mark Ryan O'Donovan
University College Cork, Ireland
Email: markrdon94@gmail.com

Dr Sara Monteiro Pires
Senior Researcher Risk Benefit Research Group
Division of Diet, Disease Prevention and Toxicology
National Food Institute, Denmark
Email: smpi@food.dtu.dk

Dr Dietrich Plaß
German Federal Environmental Agency, Germany
Email: Dietrich.Plass@uba.de

Dr Jurgen Schmidt
Public Health England, United Kingdom
Email: Jurgen.Schmidt@phe.gov.uk

Professor Stein Emil Vollset
Department of Global Public Health and Primary Care
University of Bergen, Norway
Email: Vollset@uib.no

Dr Elena Varavikova (via videoconference)
Lead Researcher
Department of Human Resources in Health Analysis
Federal Research Institute for Health Organization and Informatics of the Ministry of Health
Russian Federation
Email: dr.e.varavikova@mail.ru

Dr Thomas Ziese
Robert Koch Institute, Germany
Email: zieset@rki.de

Observer

Mr Edmond Ng

Senior Statistical Analyst
Director's Office
London School of Hygiene & Tropical Medicine, United Kingdom
Email: Edmond.Ng@lshtm.ac.uk

World Health Organization Regional Office for Europe

Ms Olga Fradkina
Programme Assistant
Division of Information, Evidence, Research & Innovation
Email: fradkinao@who.int

Dr Christian Gapp
Technical Officer
Division of Information, Evidence, Research & Innovation
Email: gappc@who.int

Dr Claudia Stein
Director
Division of Information, Evidence, Research & Innovation
Email: steinc@who.int

Annex 3. Terms of Reference

The European Burden of Disease Network (EBoDN)
Terms of Reference

Final draft

1. Preamble

Burden of disease (BoD) calculation is a method of assessing population health deficits through the analysis of mortality and morbidity, and is commonly reported using the disability-adjusted life years (DALY) metrics (among others such as healthy life years and disability-adjusted life expectancy). The DALY measure is very useful for illustrating the relative magnitude of different health concerns (such as specific diseases or risk factors), and provides a strong framework for prioritization in health policy. Despite the value of good BoD research, there is little harmonization across current studies, with considerable variations in the application of disability weights, discounting, and age-weighting, as well as whether incidence or prevalence measures are used in the calculation of years lived with disability (YLD). Of additional concern is the quality of the data that are used in BoD studies, such as their frequent update and missing or unclear data.

WHO has a tradition of providing BoD estimates for all countries. In recent years, the Institute for Health Metrics and Evaluation (IHME) has taken on a global role of estimating the BoD (expressed in DALY and other metrics) annually for all countries in the world. Member States of the WHO European Region expressed strong interest in conducting BoD studies at the national and subnational level. The Steering Group of the European Health Information Initiative (EHII), therefore, stressed the importance of harmonizing and standardizing the BoD approach across the WHO European Region, and requested that the WHO Regional Office for Europe establish a European Burden of Disease Network (EBoDN).

2. Vision, mission and aims

The **vision** of the EBoDN is to improve the health of the people in the European Region by promoting the availability and use of high-quality BoD evidence at international, national and subnational levels.

The **mission** of the EBoDN is to provide strategic guidance and leadership on harmonized, transparent, high-quality, comprehensive and comparable BoD analyses and evidence for decision-making, research, public information, and public health practice by coordinating regional expertise.

The **aims** of the EBoDN are to:

- build capacity in countries to conduct and collaborate in BoD studies for the purpose of national and international reporting requirements;
- promote the establishment of sustainable national structures and resources for BoD assessments;
- encourage countries to expand BoD assessments to the subnational level;
- build stronger links between groups in countries engaged in population health intelligence, and support knowledge exchange, communication and mutual aid between experts in the field;
- support countries to participate in international BoD collaborations;
- facilitate improvement in the availability, quality and accessibility of national health information for the purpose of BoD analysis in countries;
- harmonize BoD methodologies across the WHO European Region to ensure international comparability of results;
- improve reporting and communication of findings to facilitate the integration of BoD information into decision-making for health in all policies;
- promote good practice in the use of BoD evidence, including for the better understanding of health inequalities, including social determinants and access to care;
- promote the advantages and benefits of BoD evidence and investment in BoD studies with different stakeholders;

- advocate for the EBoDN to increase its membership; and
- support the broader goals of the EHII through the above actions.

3. EBoDN operational framework

The EBoDN will focus its activities on the following five key areas, which it deems essential for achieving its vision, mission and aims:

1. exchange of expertise, knowledge and mutual support;
2. development and application of harmonized BoD methodology and relevant tools;
3. enhanced access to and dissemination of BoD data;
4. capacity-building among interested countries; and
5. communications and advocacy.

The activities of the EBoDN are guided by two principles:

1. the development and maintenance of international, national and subnational BoD data that is harmonized, comparable, valid and reliable; and
2. accessibility and dissemination of BoD analyses to policy-makers.

In addition, several basic values underpin the work of the EBoDN:

- recognizing the necessity of an integrated and high-quality national health information system;
- recognizing the need for transparency and international comparability of BoD evidence (while mindful of national specificities);
- improving health and well-being;
- reducing inequalities; and
- enhancing national and international intersectoral collaboration on health and health-related issues.

4. Composition and membership of the EBoDN

4.1 The EBoDN is composed of its members and a Secretariat (WHO Regional Office for Europe). The members are principal investigators (or suitable representatives) of national BoD studies and experts in the European Region and representatives of the IHME.

4.2 Network membership will be assessed by the Secretariat at its sole and absolute discretion, and in accordance with WHO rules and regulations, policies and practices.

4.3 The Chairperson of the network will serve for an initial term of two years, with the possibility of renewal for an additional two-year term through re-election by the Secretariat. The Chairperson will chair the annual EBoDN meetings (and additional ad hoc meetings, see 5.2), prepare these meetings together with the Secretariat, and represent the EBoDN in different meetings related to health information, if required and subject to the conditions set out under 4.5.

4.4 A Deputy Chairperson will be selected at the first meeting and will serve for the same period as the Chairperson. The Deputy will assist the Chairperson in their duties, as required. The Deputy Chairperson will carry out the duties of the Chairperson (such as attend meetings, teleconferences, etc.) in the Chair's absence.

4.5 The EBoDN is not a legal entity, and therefore cannot undertake any action without the explicit agreement in writing of each participating state, organization, agency, institution or individual.

4.6 Any member may terminate their involvement in the EBoDN by providing written notice to the WHO Regional Office in its capacity as provider of Secretariat services to the EBoDN. In addition, the Secretariat, at its sole discretion, may terminate the participation of any member in the EBoDN.

5. Modus operandi

5.1 Subject to the availability of sufficient human and financial resources, the Secretariat will be provided by the WHO Regional Office for Europe, acting through the Division of Information, Evidence, Research and Innovation. EboDN-related communication is facilitated by the Secretariat hosted by the Regional Office (that is, through telephone conferences).

5.2 Meetings of the EBoDN will be held annually (face-to-face, if possible), with special meetings convened by the Secretariat in consultation with the Chair as required through teleconferences or videoconference.

5.3 The work of EBoDN members will be pro bono.

5.4 Due to finite resources at the Secretariat, it will not be responsible for maintaining relationships between other external organizations and networks (with the exception of the EHII).

5.5 A rapporteur will be elected at the beginning of each meeting.

5.6 Reports on the EBoDN meetings shall be submitted to the Regional Director and made available through the Regional Office’s public website.

5.7 Publications

5.7.1 As a general rule and subject to its discretion, the Secretariat shall be responsible for issuing publications about EBoDN activities. All decisions regarding the preparation and dissemination of publications made by EBoDN members (other than the Secretariat) concerning EBoDN activities shall be made by consensus. For the avoidance of doubt, dissemination of EBoDN materials will only be made by the Secretariat or as it may decide on a case-by-case basis.

5.7.2 Copyright in any publication made by the Secretariat shall be vested in WHO Regional Office for Europe. This also applies if the work is issued by the Secretariat and is a compilation of works by EBoDN members or is otherwise work prepared with input from one or more EBoDN members. Copyright in a specific separable work prepared by an EBoDN member shall remain vested in that member (or remain in the public domain, if applicable), even if it forms part of another work that is published by WHO and of which WHO owns the copyright as a whole.

5.7.3 “Publications” include any form, whether paper or electronic, and in any manner. Parties are always allowed to cite or refer to EBoDN publications, except for the purpose of promoting any commercial products, services or entities.

5.7.4 Any publication about EBoDN activities issued by an EBoDN member other than the Secretariat shall contain appropriate disclaimers as decided by WHO Regional Office for Europe, including that the content does not necessarily reflect the views or stated policy of the participating organizations, agencies and institutions (including the Regional Office, acting as the Secretariat for the network).

5.7.5 WHO shall be vested with a non-exclusive, worldwide, royalty-free and sub-licensable licence to use, reproduce, synthesize, adapt, publish and disseminate in whatever format – paper, electronic or otherwise – and in whatever manner as it may deem appropriate for public health purposes, the work produced by each EBoDN member *within the context and work of EBoDN*.[1]

6. Key functions of the EBoDN

6.1 The overall objective of the EBoDN is to improve the quality and accessibility of BoD data in the European Region through the creation of support and harmonized methodologies, and promotion of good practice in the use of BoD evidence. This will require the full commitment of participating members. For example, members should contribute by sharing BoD best practices at meetings and providing technical expertise. Information can be shared by email or other means with the Secretariat at all times. Moreover, members will provide input for the EBoDN work plan and meetings, through calls facilitated by the Secretariat (see 6.2).

6.2 In addition to the above (6.1) and as otherwise mentioned throughout this document, EBoDN members will:

[1] Please note that article 5.7.5 applies to work performed by EHII members within the context and work of the EHII. As regards the Secretariat publishing data or other information produced by others, that is data/information not produced by the Regional Office or in the context of WHO networks such as the EHII, WHO procedures prescribe appropriate acknowledgement of the copyright holder. For the reproduction of text, figures and other illustrations from non-WHO sources in WHO information products, written permission from the copyright holder is additionally required.

- meet face-to-face at least once a year, and hold additional tele- or videoconference meetings as deemed necessary by the members and the Secretariat;
- inform and consult with the WHO Regional Office for Europe regarding any changes to the structure, modus operandi and/or content of the EBoDN and directly support the Regional Office in the coordination of this effort;
- inform the WHO Regional Office for Europe on all strategic matters pertaining to the EBoDN;
- support the WHO Regional Office for Europe on the development of concrete annual work plans for the EBoDN and their implementation; and
- manage relationships with all other external organizations and networks with the exception of the EHII, which will be addressed by the Secretariat.

7. Liability

Under no circumstances shall WHO assume any liability for acts carried out by EBoDN members regardless of whether such acts were carried out in the name of the EBoDN. Furthermore, the Secretariat at its sole discretion may refrain from implementing any decision of the EBoDN if in the view of the Secretariat, such decision gives rise to undue financial, legal or reputational liability or is contrary to WHO rules, regulations, administrative practices and programmatic and technical policies.

8. WHO Name and Emblem

Without the prior consent of the Secretariat, no member shall, in any statement or material of an advertising or promotional nature, refer to its relationship with WHO or use the name and emblem of WHO.

9. Amendments

These Terms of Reference may be amended by the Secretariat, and all EBoDN members shall be informed of such changes and shall be required to endorse them as a condition for their continuing participation in the network.

Annex 4. Work plan

Priority activities	Description of activity	Core deliverable	Priority	Lead	Timeframe			
					2016		2017	
					Q3	Q4	Q1	Q2
Strategic activities								
	Ensure sustainability of BOD work at the national level	Rationale (& generic benefits) to support national bids for resources to perform BOD studies		Dietrich Plaß			X	
	Establish Working Group for the finalization of BoD Manual		1	WHO Regional Office for Europe		X		
	Articulate what the network requires from WHO, IHME and governments to proceed	An EBODN manifesto		All		X		
	Provide a strategic forum to articulate the strengths and weaknesses of different approaches to, and operational requirements of, BoD studies	Plan half-day section for next in-person meeting to discuss		WHO Regional Office for Europe		X		
	Outreach to potential members			Sara Monteiro Pires		Next 6 months		
	An inventory of networks and groups working with BoD			Ian Grant & Peter Allebeck		x		
	Promote access to data	Review reports from IHME on data revision		All/IHME to provide reports	Throughout		X	
	Link IHME and EHII (and extend an invitation to join EHII)			WHO Regional Office for Europe			X	
	Ensure the appropriate use of BoD results in practice	Report back on experience		All				X
	Identify opportunities for BoD training and translation of material into national languages			All				X
Technical activities								
Provide technical expertise and share experience	Contribute to the development of national BoD manual	• Review meeting • Technical input into the draft • Review of final draft as group		Members of Working Group			X X	
	Contribute methodological expertise to international collaboration	Sign-up to collaborate and peer-review GBD analyses		All (on voluntary basis)				
	Suggest changes to GBD dimensions (including diseases, risk factors, subnational analyses)			All				
	Contribute to tools			All				
	Collate experience of effective use and communication of BoD evidence Share experience of international collaboration Share experience of operational requirements (including resources) for conducting BoD studies	Summary report (including case studies) How-to guide to international collaboration		Brecht Devleesschauwer			X	
Create EBoDN website	Identify and promote information about international and national BoD activities	Website		WHO Regional Office for Europe			x	
	Organize a sharing platform	Dropbox folder to share bibliography of studies		WHO Regional Office for Europe	x			

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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World Health Organization
Regional Office for Europe

UN City, Marmorvej 51, DK-2100 Copenhagen Ø, Denmark
Tel: +45 45 33 70 00 Fax: +45 45 33 70 01
Email: eucontact@who.int
Website: www.euro.who.int