

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

Oslo, Norway
23–24 August 2017





**World Health
Organization**

REGIONAL OFFICE FOR **Europe**

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ABSTRACT

The second meeting of the European Burden of Disease Network (EBoDN) was convened by the WHO Regional Office for Europe on 23–24 August 2017 in Oslo, Norway, and hosted by the Norwegian Institute of Public Health. A range of national and international burden of disease (BoD) experts from Europe and the Institute for Health Metrics and Evaluation (IHME) attended the meeting. The purpose of the second meeting was to further enhance collaboration; to discuss and agree on development of the BoD manual; and to facilitate effective knowledge exchange between experts in the field. Considerable progress has been made since the first meeting: a draft of the BoD manual has been produced; an editorial on the formation of the EBoDN has been published in the *European journal of public health*; several countries have managed to produce subnational BoD estimates; and IHME has secured funding for the next 10 years. However, participants also described various challenges facing those undertaking BoD studies, including capacity and funding, engagement from stakeholders, and access to high-quality data. The next steps will be to continue collaboration and knowledge transfer between countries, to expand the network in breadth and depth, and to finalize the BoD manual. A work plan for the next year was agreed to realize these aims.

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Abbreviations

BoD	burden of disease
EBoDN	European Burden of Disease Network
EHII	European Health Information Initiative
EUPHA	European Public Health Association
EVIPNet	Evidence-Informed Policy Network
GBD	global burden of disease
IANPHI	International Association of National Public Health Institutes
IHME	Institute for Health Metrics and Evaluation
PHE	Public Health England
RKI	Robert Koch Institute
WHO	World Health Organization

Executive summary

The second meeting of the European Burden of Disease Network (EBoDN) was convened by the WHO Regional Office for Europe on 23–24 August 2017 in Oslo, Norway, and hosted by the Norwegian Institute of Public Health. The meeting was attended by a range of national and international burden of disease (BoD) experts from Europe (including Norway, Germany, Sweden, France, the United Kingdom, Belgium, Switzerland, the Russian Federation and Serbia) and by representatives from the Institute for Health Metrics and Evaluation (IHME) and the WHO Regional Office for Europe. The BoD Manual Working Group met on 22 August 2017, the day before the EBoDN meeting.

Considerable progress has been made since the first meeting: a draft of the BoD manual has been produced; an editorial on the formation of the EBoDN has been published in the *European journal of public health*; several countries have managed to produce subnational BoD estimates; and IHME has secured funding for the next 10 years. Furthermore, the European Health Information Initiative (EHII), which aims to improve data interoperability and harmonization across the European Region, may provide opportunities for BoD studies to optimize data use.

Participants described a spectrum of progress and approaches to BoD across Europe. A few countries have been working on BoD for several years and have started to generate subnational BoD estimates, whereas others are just starting to engage with national estimates. Participants also described various challenges facing BoD studies that have so far been undertaken. These included: sustainable capacity and funding, especially with respect to personnel required for data management and funding of BoD studies; engagement from stakeholders, such as governments, academics and data custodians, because of methodological concerns or political influences; and insufficient access to high-quality data, which has led to data gaps. Participants shared examples of national successes, such as Norway undertaking national surveys to fill data gaps, IHME publishing methodological papers specifically for Brazil to improve engagement, and the United Kingdom working with a number of universities on specific topics or areas.

The meeting achieved its purpose of further enhancing collaboration, discussing and agreeing on development of the BoD manual, and facilitating effective knowledge exchange between experts in the field. The expected outcomes achieved were as follows.

a) Agreement on the content and future steps for finalization of the BoD manual

Significant progress has been made since the signing of a memorandum of understanding between WHO and IHME to produce a freely accessible and regularly updated BoD manual. The purpose of the manual is to provide a practical guide that reflects advances in methodology and gives guidance on how to undertake national BoD studies, signposting to other resources, and a description of the strengths and limitations of various approaches. More detail about the manual can be found in the report of the BoD Manual Working Group meeting. The main sections of the manual will include: 1) key components; 2) summary information on conducting a national BoD study; 3) conducting a national BoD study: data, analysis, indicators; 4) analytic components; 5) subnational BoD; and 6) resources and opportunities. It is expected that a final version will be produced in 2018.

b) Identification of potential new areas of work

Participants were keen to expand the EBoDN, while acknowledging that it should not become too large and unmanageable. Expansion should include adding new members, strengthening collaboration between countries, and linking with other relevant networks. Supporting BoD knowledge translation within and between countries and organizing appropriate training were also identified as an important area of future work.

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c) Agreement on the revised EBoDN work plan

A detailed work plan detailing specific strategic and technical activities was produced to cover the period until the end of 2018 and is shown in Annex 2.

d) Production of a report

This report summarizes the discussions held, conclusions reached, and action points agreed at the meeting.

The next steps will be to continue collaboration and knowledge transfer between countries, to expand the network in breadth and depth, and to finalize the BoD manual. A work plan for the next year was agreed to realize these aims.

Introduction

The second meeting of the European Burden of Disease Network (EBoDN) was convened by the WHO Regional Office for Europe on 23–24 August 2017 in Oslo, Norway, and hosted by the Norwegian Institute of Public Health (see Annex 1 for the programme). The meeting was attended by a range of national and international burden of disease (BoD) experts from Europe and the Institute for Health Metrics and Evaluation (IHME) (see Annex 3 for the list of participants). The BoD Manual Working Group met on 22 August 2017, the day before the EBoDN meeting.

The meeting was opened by Dr Camilla Stoltenberg (Director-General of the Norwegian Institute of Public Health), Professor John Newton (Chief Knowledge Officer, Public Health England and Chair of the EBoDN) and Dr Claudia Stein (Director, Division of Information, Evidence, Research and Innovation, WHO Regional Office for Europe).

Dr John Ford was elected as rapporteur. The programme was adopted.

Objectives of the meeting

The purpose of the second meeting of the EBoDN was to further enhance collaboration among a diverse group of countries that share similar aims; to discuss and agree on development of the BoD manual; and to facilitate effective knowledge exchange between experts in the field. The expected outcomes were:

- agreement on the content and future steps for the finalization of the BoD manual;
- identification of potential new areas of work;
- agreement on the revised EBoDN work plan;
- a report summarizing the discussions held, conclusions reached, and action points agreed at the meeting.



Update on recent developments in the field of BoD and related areas in the WHO European Region

The European Health Information Initiative (EHII) is committed to improving the information that underpins health policies across Member States of the WHO European Region by focusing on coordination, harmonization and integration of health information and its systems (1). At the time of writing this report, the EHII had 34 participants including a range of other interested organizations (e.g. Organisation for Economic Co-operation and Development, Wellcome Trust, IHME, European Commission and European Public Health Association (EUPHA)). The EHII has six key areas of work:

1. Development of information for health and well-being with a focus on indicators
2. Enhanced access to and dissemination of health information
3. Capacity building
4. Strengthening of health information networks
5. Support for health information strategy development
6. Communication and advocacy.

Developments within the EHII have implications for national and international BoD projects within the European Region. These include: a desire to reintroduce country health and well-being profiles and to highlight documents which could include BoD results; the launch of a new bilingual (English and Russian) public health journal for the Region (*Public health panorama*), which may be a vehicle for BoD dissemination (2); inclusion of a BoD module presented by IHME at the annual Autumn School on Health Information and Evidence for Policy-making; and opportunities to support other EHII-associated networks, such as the South-eastern Europe Health Network, to develop BoD work. The goal of the EHII is interoperability and harmonization of data within the Region. This would not only reduce the reporting burden for individual countries but could also improve data quality. BoD would be a direct beneficiary of, and possibly contributor to, this data integration. Furthermore, WHO is working with other organizations to reduce the burden of reporting, for example by a joint set of indicators with reporting at agreed intervals.

Update on recent developments in the field of BoD and related areas at national level by participants

Participants from nine different countries reported on BoD developments (Norway, Germany, Sweden, France, the United Kingdom, Belgium, Switzerland, the Russian Federation and Serbia). A few countries, such as Norway, Sweden and the United Kingdom, have been working on BoD for several years and have started to generate subnational BoD estimates; other countries, such as France, are just starting to engage with national estimates. There is also a spectrum of approaches seen across Europe with respect to the way in which BoD studies are undertaken. For example, in the United Kingdom, Scotland has undertaken its own BoD analyses, drawing on IHME methodology, because there are local contextual concerns about the disability weights and prevalence estimates generated by IHME. Most other countries are using the estimates provided by IHME. There is also a range of different specific policy interests within countries, such as air pollution, mental health, and drug and alcohol use.

There were three common themes reported by participants.

1. Capacity and funding

All participants reported the difficulty of undertaking BoD projects with limited resources – in particular, a lack of sufficient personnel resources in the area of data management. While there may be a number of GBD (global BoD) collaborators within a country, many of these are disease-specific experts, with relatively few people taking a broad overview. Countries that have managed to develop BoD projects

have usually had support from the Ministry of Health (or equivalent) and national institutes of public health.

Linked to this issue is the challenge of securing funding for BoD work. BoD projects seem to fall between descriptive epidemiology and research. Some research funders are therefore unwilling to fund BoD projects because they are too descriptive and not sufficiently analytical. Health ministries (or their equivalent), on the other hand, seem to be less likely to fund BoD projects because they are viewed as being similar to research.

2. Engagement from stakeholders

A number of participants spoke about the difficulties of engaging with stakeholders within their country, such as government, academics and data custodians. There were various reasons cited for this lack of engagement, including concerns about the methodology of BoD studies, political influences, and lack of familiarity with outcome measures (such as disability-adjusted life years, or DALYs). Poor engagement made it more difficult to disseminate BoD findings, reducing their potential impact.

Countries with better BoD engagement reported a history of evidence-informed policy-making, successful communications campaigns and broad engagement. For example, in the United Kingdom, Public Health England (PHE) is working with up to six universities in BoD, while in Scotland voluntary organizations and charities have expressed such interest in BoD estimates that a three-day event to present the results has been organized. BoD experts from Germany successfully collaborate with an insurance company to access additional data.

Participants from IHME reported that there had been greater engagement in Brazil after a series of publications, including methodological papers, that were bespoke to the country (3).

3. Access to high-quality data

Lack of funding, capacity and engagement from stakeholders has led to limited access to suitable data to inform BoD models. For example, some participants reported that disengaged academics expected academic recognition or payment for providing data for BoD studies to cover the cost of data management; other participants noted that a lack of capacity and funding for data management had made it more difficult to improve the quality of data underlying BoD models. Participants noted that data custodians were often more willing to share data with WHO than with IHME and suggested that a WHO endorsement might encourage more people to share data. Furthermore, lack of consistency in case definitions and coding, such as inconsistent use of ICD codes, was reported to be a problem.

Data gaps were reported to be a common problem. Some participants reported that they had been able to undertake or modify national surveys either to fill these gaps or to update estimates that were out of date. For example, Norway is currently undertaking a survey to obtain more up-to-date mental health estimates because the current estimates date back to the 1990s. Rapid response projects – brief studies undertaken to answer a focused epidemiological question – were discussed as an alternative. It was recognized that harmonization of surveys across the Region would be useful.

Participants from Sweden reported the potential future use of individual-level data to inform BoD studies. However, a major barrier will be information governance processes, which currently do not allow this level of data to be shared internationally. One possible solution would be to undertake the analysis within the country and export summary-level data.

Update from IHME

IHME has secured \$279 million for the next 10 years of GBD; this will be used to understand the world's major health problems, how societies are dealing with them, and how best to direct resources towards alleviating them. IHME continues its close collaboration with the WHO Regional Office for Europe,

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supported by the memorandum of understanding (4), to develop the BoD manual, support training and raise awareness of GBD.

Since the meeting, the next wave of GBD data has been published (5). As part of this analysis, IHME has now produced subnational estimates for the Russian Federation, Norway, India, the United Kingdom (England), Ethiopia, Iran and New Zealand, although not all of these have been published. The subnational estimates for New Zealand are based on ethnicity (Maori versus non-Maori).

GBD publications are now compliant with the Guidelines for Accurate and Transparent Health Estimates Reporting (GATHER), improving the transparency of the studies. Considerable work has gone into further improving the online resources.

Future developments will include tracking health spending and forecasting GBD for the next 35 years.

Update on the BoD manual

The first meeting of the EBoDN's BoD Manual Working Group was held on 22 August 2017, the day prior to the main EBoDN meeting. A separate report will be produced to summarize the discussion and actions of the working group. During the EBoDN meeting an update on progress of the BoD manual was given by Professor Stein Emil Vollset.

In May 2015, a memorandum of understanding between WHO and IHME included an ambition to produce a manual on conducting national BoD studies (4). The purpose of the manual is to provide a practical guide that reflects advances in methodology and gives guidance on how to undertake a national BoD study, signposting to other resources, and a description of the strengths and limitations of various BoD approaches. The manual recognizes that BoD studies cover a spectrum ranging from those that rely only on IHME infrastructures to those that are completely stand-alone. A first draft of the manual was produced in August 2016. Since then it has undergone three further iterations based on comments from national BoD experts.

Currently the main sections of the BoD manual include:

1. Key components of BoD
2. Conducting a national BoD study, summary information (e.g. capacity and infrastructure)
3. Conducting a national BoD study: data, analysis, indicators
4. Analytic components
5. Subnational BoD
6. Resources and opportunities.

The manual will be produced in a way that is neutral and value-free – not advocating one approach or organization, but rather describing the strengths and limitations of different approaches.

A further revision is planned for December 2017, with a final version due in 2018.

Recent and potential publications

An editorial was published in the *European journal of public health* on the formation of the EBoDN; it was authored by the EBoDN Chair and the WHO Regional Office for Europe Secretariat (6). There has also been extensive work mapping all European BoD studies, documented in a paper now in press with the same journal (7).

Dietrich Plass wrote a short report about the EBoDN for the WHO Collaborating Centre for Air Quality Management and Air Pollution newsletter (8).

IHME produces a newsletter for collaborators and would like to include any publications arising from the EBoDN.

Areas for further development and next steps

Participants were keen to see the EBoDN grow by increasing the membership, improving communication about the network's purpose, and strengthening collaboration between countries. There was a desire to expand the network by adding new national expert members, but without it becoming too large. Some countries may be interested in developing BoD projects, but lack the necessary expertise. There may also be opportunities to link with other networks, such as the International Association of National Public Health Institutes (IANPHI). EBoDN membership may not be suitable for everyone, and these individuals could join future meetings as observers. In addition, participants wanted the EBoDN to continue to share good practice and to be a forum in which the strengths and limitations of BoD studies can be articulated.

Participants will continue to work on the BoD manual; its publication will be a significant achievement for both the EBoDN and IHME.

Participants recognized that BoD knowledge translation – taking BoD estimates to policy-makers to influence decisions – would be an important next step. WHO's Evidence-Informed Policy Network (EVIPNet) supports knowledge translation by bringing together a range of stakeholders and helping to establish mechanisms to translate evidence into policy. In the United Kingdom knowledge translation has been facilitated by involving three main groups: academics, public health practitioners and policy-makers.

Participants acknowledged the need for better training around BoD. Funding may become available for two EBoDN workshops over a three-year period through the European Commission's Joint Action Plans programme. Attempts will also be made to organize a BoD workshop at the EUPHA Conference 2018. Participants will share any national BoD training with the network.

Conclusions and next steps

The second meeting of the EBoDN sought to deepen collaboration and knowledge transfer between national experts in BoD studies. Significant progress has been made by the EBoDN and IHME in developing a BoD manual. There have been several positive developments in BoD studies – notably, generating subnational estimates and securing funding for the next 10 years of GBD work at IHME. However, various challenges remain for those undertaking BoD studies, including capacity and funding, engagement from stakeholders, and access to high-quality data. The next steps will be:

- to continue collaboration and knowledge transfer between countries;
- to expand the network;
- to finalize the BoD manual in 2018.

An action plan for the next year was agreed in order to realize these aims.

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Annex 1. Programme

Wednesday, 23 August 2017

- 08:30–09:00 Registration
- 09:00–09:25 Welcome and opening remarks
Official opening by Dr Camilla Stoltenberg, Director-General of the Norwegian Institute of Public Health, Professor John Newton, Chair of the EBoDN, and Dr Claudia Stein, WHO Regional Office for Europe
- 09:25–09:40 Introduction of participants
- 09:40–09:45 Selection of the rapporteur
Professor John Newton, Chair
- 09:45–09:55 Adoption of the programme
Professor John Newton, Chair
- 09:55–10:25 Update on recent developments in the field of BoD and related areas in the WHO European Region
WHO Secretariat
- 10:25–10:50 Coffee break and group photo
- 10:50–11:50 Update on recent developments in the field of BoD and related areas at national level by participants
All
- 11:50–12:00 Update by Chair
Professor John Newton, Chair
- 12:00–13:00 Presentation of the BoD manual (*IHME*)
Discussion
- 13:00–14:00 Lunch break
- 14:00–15:00 Presentation and discussion of the results of the First meeting of the BoD Manual Working Group
Spokesperson of the working group
Discussion
- 15:00–15:15 Reflections on and summary of day 1
Chair, WHO Secretariat, IHME
- 19:00 Dinner

Thursday, 24 August 2017

- 09:00–09:15 Summary of the key points outlined in day 1 and expectations for day 2
Rapporteur, WHO Secretariat
- 09:15–10:30 Presentation and discussion of the results of the First meeting of the BoD Manual Working Group (continued)
Spokesperson of the working group
Discussion
- 10:30–10:45 Coffee break

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- 10:45–11:15 Discussion of the results of the First meeting of the BoD Manual Working Group and agreement on next steps
Professor John Newton, Chair
- 11:15–11:45 Recent and potential new publications of the EBoDN
All
- 11:45–12:30 Attracting new members to the network
Chair, all
Discussion
- 12:30–13:30 Lunch break
- 13:30–15:00 Revision of the EBoDN work plan
All
- 15:00–15:15 Coffee break
- 15:15–16:15 Next steps and date of the next meeting
All
- 16:15–16:45 Closing remarks
Professor John Newton, Chair

Annex 2. Work plan

Priority activities	Description of activity	Core deliverable	Priority	Lead	Timeframe									
					2016		2017		2018					
					Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Strategic activities														
	Ensure sustainability of BoD work at the national level	Rationale (and generic benefits) to support national bids for resources to perform BoD studies		Dietrich Plass, Brecht Devleeschauwer						X				
	Establish working group for finalization of BoD manual		1	WHO Regional Office for Europe		X								
	Develop and publish BoD manual	Interim draft		IHME						X				
		Final draft for discussion with WHO and WHO regions		IHME							Spring 2018 (pending IHME confirmation)			
	Articulate what the network requires from WHO, IHME and governments to proceed	An EBoDN manifesto		All		X								
	Publish manifesto on WHO/Europe website			WHO					X					
	Provide a strategic forum to articulate the strengths and weaknesses of different approaches to, and operational requirements of, BoD studies	Plan half-day session for next in-person meeting to discuss		WHO Regional Office for Europe					X Done on 22 Aug 2017					
		Outputs of discussion to become a part of meeting report and a part of BoD manual								X				
	Outreach to potential members			Sara Monteiro Pires		Next six months								
		WHO call for experts (developing BoD group in its current form)		WHO						X				

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		Engage IANPHI in promotion of BoD		PHE/John Newton									X		
		Explore options for a BoD workshop in EUPHA 2018		RKI/Thomas Ziese (EUPHA/EHII focal point to be potentially involved)								X			
		To support development of the Joint Action on Health Information in relation to BoD		PHE/John Newton Santé publique France/Anne Gally									X		
		To take forward/report actions from the Joint Action		PHE/John Newton Santé publique France/Anne Gally									X		
	An inventory of networks and groups working with BoD			Ian Grant and Peter Allebeck		X									
		Collect information on other European networks/groups doing any BoD work and provide to Secretariat		All						X					
	Promote access to data	Review reports from IHME on data revision		All/IHME to provide reports	Through-out		X								
		Draft a discussion paper on improving availability of data for the next meeting		Brecht Devleeschauwer, Stein Emil Vollset, Thomas Fürst, Ian Grant, IHME									X		
	Link IHME and EHII (and extend an invitation to join EHII)			WHO Regional Office for Europe			X								
	Ensure appropriate use of BoD results in practice	Report back on experience		All				X							X
	Identify opportunities for BoD training and translation of material into national languages			All				X							X

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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