Population Health Metrics

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Towards a burden of disease research agenda

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Abstract

Disability-Adjusted Life Years (DALY) have become a common metric for assessing the combined effects of morbidity and mortality. However, the lack of resources and/or input data, combined with the complexity of the methodological framework, resulted in major disparities in research capacity and knowledge about burden of disease estimations across Europe. Since 2019, the European Burden of Disease (burden-eu) Network has been acting as a technical platform for strengthening capacity in burden of disease assessments. The burden-eu network developed a forward-looking research agenda, identifying four key burden of disease themes: transparency and availability, method refinement, potential expansions, and specific topics. The research agenda's priorities can be used to prioritise and guide the design of studies in the burden of disease framework.

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Introduction

Population health monitoring is crucial for understanding disease impact and trends to guide policies. This requires comprehensive indicators that combine morbidity and mortality to account for both longevity and quality of life as life expectancy increases [1]. Since the first publication of the Global Burden of Diseases, Injuries and Risk Factors (GBD) study in 1993, the use of Disability-Adjusted Life Years (DALY) has become increasingly common to monitor population health. The DALY combines morbidity and mortality effects in one comprehensive and comparable metric [2]. In particular, DALYs are useful for quantifying and ranking the burden due to specific causes and can help understand whether improvement occurs over time [3]. Driven by the impact of the GBD study, several researchers and national and international health institutes have adopted the burden of disease (BOD) approach [4]. However, the lack of resources and/or input data, combined with the complexity of the methodological framework, resulted in major disparities in research capacity, knowledge and experience with BOD across Europe [4]. The European Burden of Disease Network (burden-eu) started in 2019, intending to

address these challenges by acting as a technical platform for integrating and strengthening capacity in BOD assessments across Europe and beyond [5].

The burden-eu network sought to develop a research agenda based on barriers and weaknesses identified through the network activities, while also pinpointing gaps in the current analysis. In this paper, we document the process and present the outcomes of a forward-looking research agenda for BOD studies, providing specific examples of its practical use in the research field.

Methods

To develop a research agenda for BOD studies, we followed a multi-step approach:

1. Review of evidence to identify possible gaps or future research topics;
2. Analysing and detailing the characteristics of the research questions identified;
3. Prioritising research questions identified and adding examples for their practical application.

The first two steps were developed through the activities of the burden-eu network and the input of the network members. Subsequently, all the possible action points were categorized, evaluated and prioritized in the BOD research agenda. Figure 1 depicts the aims, sources, and outputs of our approach.

Activities within the burden-eu network

The burden-eu network amassed close to 500 members from 66 different countries, as well as many partner institutions, including the World Health Organization (WHO) and the Organisation for Economic Cooperation and Development (OECD). Some of the most relevant activities of the network were capacity-building activities (e.g. short-term scientific missions, training schools), scientific presentations, including webinars, and published peer-reviewed papers. These activities highlighted key challenges for researchers in this field, which were translated into possible research questions.

Members consultation

Network members were consulted for each of the three aims of the process (Fig. 1). Initially, members were consulted via an online questionnaire. This was sent to all network members in September 2023. Seventy-nine respondents answered the following questions: *"What are the limitations or pitfalls of the burden of disease methods as used today?";* and *"What are the possible expansions of the burden of disease framework? In other words, what are other domains that could be part of the burden of disease framework?".*

The questionnaire results identified potential research questions, grouped into themes. The members of the network that participated in the 2023 annual meeting (69 participants in Tallinn, Estonia, September 2023) participated in a structured group discussion. Firstly, they were asked to prioritize questions using Wooclap

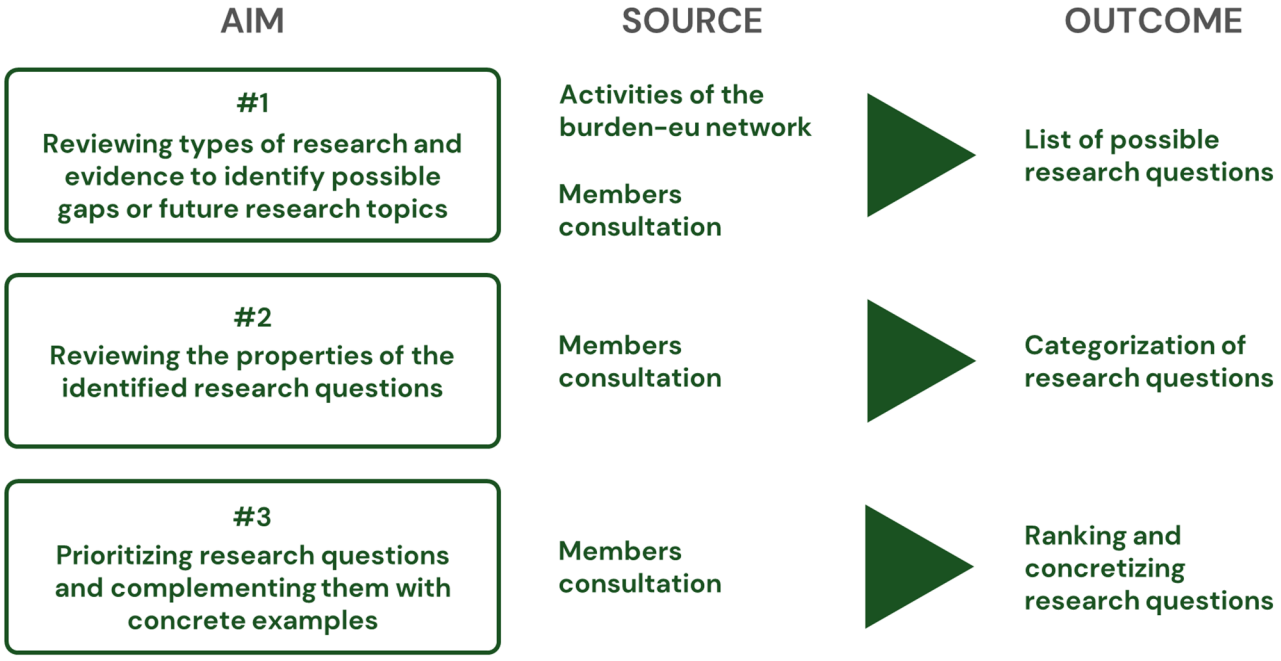

Fig. 1 Description of the approach used to compile the research agenda with the aims, sources and outcomes

Table 1 Identified research questions and domains, ranked according to the points received (from highest ranked to lowest ranked)

Transparency and availability of the BOD framework	Refining current methods of the BOD framework	Possible expansion to new applications	Development of specific topics in the estimation of BOD
Transparency of methods (16.2% of points)	Adjustment for multi-morbidities (21.8%)	Social determinants of health (21.2%)	Burden of syndemics (i.e. burden of clusters of diseases, and clusters of risk factors, that are frequently seen in the population) (13.9%)
Availability of primary data sources (13.5%)	Account for multiple exposures to environmental stressors (20.8%)	Integration in economic evaluation (18.4%)	Burden of natural disasters (12.3%)
Discussion on limitations and application of methods (12.2%)	Discussion on the exposure-response functions form (18.2%)	Using BOD estimates to extrapolate the parameters of health care services/utilization (12.4%)	Focus on novel upstream risk factors (i.e. climate change) (12%)
Availability of easy-to-access guidelines (10.7%)	Country-specific disability weights (17.7%)	Impact of health system organization (pricing and reimbursement) on BOD (11.5%)	One health (10.8%)
Guidelines for implications of BOD in the decision-making process (10.4%)	Improve sustainability of estimates (12.3%)	Applying Artificial Intelligence methods (11.2%)	Elderly-specific disorders (10.4%)
Availability of ready-to-use tools for estimation (10.4%)	Applying the International Classification of Functioning (9.3%)	Foresight (10.8%)	Children and maternal health (9.4%)
Availability of universally recognized standards (9.6%)		Monetization of DALY (10.3%)	Frailty (7.4%)
Homogeneity of methods (8.9%)		Creating taxonomies or propose Common Data Elements (4.1%)	Burden of violence and/or terrorism (6%)
Facilitate data sharing (8.2%)			

BOD: Burden of Disease; DALY: Disability-Adjusted Life Years

In parenthesis the proportion of points attributed to the item, within the specific question

by distributing points. Finally, they refined the questions with defined research actions.

Results

The collection exercises led to a list of research questions and four themes: transparency and availability of the BOD framework, refining current methods, possible expansion to new applications of the BOD framework, and development of specific topics in the estimation of BOD (Table 1).

Transparency and availability

This theme emphasizes the need for greater transparency in BOD studies, including thorough documentation of methodological choices and input data reporting. Literature reviews identified the lack of reporting guidelines as a major challenge, affecting accuracy and comparability [6]. Additionally, the limited availability of primary data sources (e.g. mortality and disease registries) posed a common challenge for many countries. Participants highlighted the usefulness of capacity-building activities (such as training schools and short-term scientific missions) and adopting an "open science" approach to enhance transparency.

Refining current methods

This theme collects the research questions that drive improvements in methods currently used in BOD studies. These involved key input parameters such as exposure-response functions and disability weights, but also more advanced methodologies like adjustments for the co-occurrence of diseases, sequelae, and interplay of exposures.

To advance on these issues, available datasets containing information on multiple outcomes or exposures and the interaction between both could be leveraged. In the review of the BOD studies on risk factors, the partially scarce information on causal statements of risk-outcome-pairs was pointed out [7]. Causal inference was proposed as a potential method to better investigate stronger causal links between exposure and outcome.

Possible expansion to new applications

This theme was developed to summarize the research questions, aiming to expand the applications of BOD beyond its current use. Two elements were considered as priorities: social determinants of health and economic evaluations. The latter was more generally connected to the use of BOD estimates in health economic aspects, like monetization of DALY and healthcare utilization. Some concrete examples of how BOD could be used in this domain were the use of DALY in health impact assessments and economic evaluations. As for the social determinants of health, some initial reflections on its application included burden stratification by socio-economic status (SES), computing population attributable

fractions for SES, or including multiple deprivation indices.

Topics

This theme includes the possible topics (novel or otherwise) for future BOD studies. The burden of syndemics was the one that was given most of the points (Table 1). This refers to the interaction of two or more diseases within a population, which exacerbates the effects of each other. This phenomenon has implications in the computation of BOD estimates, as synergy implies that the BOD attributable to joint health risks exceeds the sum of the disease burden of the health risks in isolation [8]. The burden of natural disasters and novel risk factors (e.g. climate change) closely followed and highlighted the importance of strengthening the "one health" approach.

Discussion

The numerous challenges faced by researchers conducting national BOD studies highlighted the need for joint efforts. Our BOD research agenda aimed to identify themes and to understand their relative importance, given limited resources.

We identified four main themes: transparency and availability, refining current methods, possible new expansions, and topics. In general, there is a clear agreement on the need for greater transparency and improved access to data and resources to enable and/or facilitate the calculation of BOD estimates at the national level. To address the transparency gaps, the network members developed the Standardised Reporting of Burden of Disease Studies (STROBOD) statement. It is designed to be a standard protocol for reporting DALY calculations [9]. By addressing one of the key priorities outlined in our research agenda, the STROBOD statement promotes greater consistency and transparency, thereby improving the utility and reliability of BOD estimates. The STROBOD statement is a tool that focuses on the specific methodological choices of the DALY estimation, in contrast to broader and more general statements (e.g. GATHER and CHEERS).

The agenda also emphasized the necessity of improving certain BOD methodologies. One key area of discussion was exposure-response functions, as well as the understanding and establishment of causal relationships between exposures and outcomes. In this context, the GBD study has made methodological advancements, including the Burden of Proof approach [10]. This enables researchers to more accurately interpret the strength of evidence for causal associations between exposures and outcomes, but it still does not fully account for the impact of confounders. Current examples of estimations of exposure-response functions in the framework of causal inference deal with environmental exposures [11,12].

The research agenda also highlighted the potential of integrating BOD estimations in health economics. The OECD is developing several methods that complement BOD analyses [13]. In its simplest form, the economic component is added by calculating the healthcare costs caused by the diseases. A more comprehensive approach is the use of monetary values to measure the extent to which individuals are willing to exchange their income for health outcomes. Finally, in its most advanced and comprehensive form, analyses can include assessments of several relevant dimensions, such as those in the OECD's Better Life Index [14].

Next steps

A key next step for the implementation of the research agenda is its successful dissemination. The present publication will serve as a platform for dissemination in the scientific community. The research agenda was already presented at the 2024 European Public Health Conference (Lisbon, Portugal) and shared with a wide range of stakeholders. It will also be distributed through the networks' newsletter and website (https://www.burden-eu.net/). The research agenda is addressed to researchers and public health organizations who can prioritize and design studies based on the agenda's priorities. In the coming years, the burden-eu network will focus on translating the agenda into practice. The network will incorporate the research priorities and methodologies in its capacity-building activities. The growing network will ensure that the research agenda is a "living document". The research agenda will be updated as needed to reflect new knowledge, emerging challenges, and evolving priorities. Its impact will be assessed via different indicators, e.g. how many times the agenda was referenced and the number of studies that addressed one or more of the priorities identified in the agenda published.

Acknowledgements

We would like to acknowledge the time, effort, and responses from members of the burden-eu network, which form the basis of the research agenda presented in this manuscript. The ideas presented in this manuscript represent the collective view of participants and do not necessarily represent the individual perspectives of co-authors of this manuscript.

Author contributions

The paper is based on the expertise collected from the burden-eu network. VG wrote the manuscript with input from all authors. All the authors approved the manuscript.

Data availability

No datasets were generated or analysed during the current study.

Declarations

Patient and Public Involvement

It was not appropriate to involve patients or the public in the design, or conduct, or reporting, or dissemination plans of our research, as our research specifically targets researchers.

Competing interests

The authors declare no competing interests.

Received: 15 July 2025 / Accepted: 24 February 2026
Published online: 26 March 2026

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