

Burden of disease studies supporting policymaking in the European Union: a systematic review

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Abstract

Burden of disease (BoD) studies quantify the health impact of diseases and risk factors, which can support policy-making, particularly in the European Union (EU). This study aims to systematically analyse BoD studies, which address EU public policies to contribute to the understanding of its policy uptake. A systematic search of six electronic databases and two grey-literature registries was carried out for articles published between 1990 and 2023. The thematic area, type of legislation and the respective policymaking stage were extracted. A textual analysis of the discussion was conducted to assess the inclusion of specific EU policy implications. Overton was used to detect citations in policy documents. Out of the 2054 records screened, 83 were included. Most studies employed secondary data, with 37 utilizing GBD data. Disability-adjusted life year was present in most of the studies ($n = 53$). The most common type of the EU legislation mentioned was the directive ($n = 47$), and the most frequent topic was environment ($n = 34$). Policy implications for EU laws were discussed in most papers ($n = 46$, 55.4%), with only 8 conducting evaluation of EU policies. Forty-two articles have been cited at the EU-level, in a total of 86 EU policies. Despite increasing efforts in integrating EU legislation impact within BoD studies, these results denote a low consideration of the legal and policy changes. Greater efforts in directing research towards policy effectiveness evaluation might increase their uptake in EU policies.

Introduction

Burden of disease (BoD) studies quantify the health impact of diseases and risk factors in comparable metrics. The disability-adjusted life year (DALY) is a widely used health metric, which is at the core of global burden of disease (GBD) studies. Two parameters are generally necessary to estimate BoD: years lived with disability (YLD), and years of life lost (YLL) due to premature mortality, capturing both morbidity and mortality [1]. The number of BoD studies has increased across the years, especially since 2015 in the case of infectious diseases [2], and with progressive harmonisation of the BoD methodology. The BoD indicators are nowadays widely accepted and can be utilized for supporting evidence-informed policymaking in several fields, including environment and health [3].

BoD metrics have also been used for health impact assessment and cost-effectiveness analysis, providing an associated monetary value [4]. This is useful for selecting or evaluating interventions and policies, which could potentially play a role in influencing the final policy choice or even supporting a new policy [5]. As such, policy-oriented research using BoD metrics has the potential to produce evidence, which allows supporting public policies [6]. This can happen in all policy cycle stages, most notably policy evaluation and formulation, including agenda setting [7].

Knowledge translation (KT), which defines a set of processes focusing on generating, exchanging, and incorporating research into policies, is an important pillar for better usage of BoD metrics [8]. The usage of generated BoD data can depend on several factors, such as how accessible, relevant, and timely the research is for policymakers. Important aids in communication and dissemination of BoD research to policymakers include different data visualization

elements, as they can be employed to grasp the results and incorporate them into ongoing or future policies [9].

The Treaty on the Functioning of the European Union emphasizes the role of the European Union (EU) in protecting and improving human health, through public health measures. The Union has the power to support, coordinate, or complement public health actions of member states in line with the Treaty, as these have autonomy in health policymaking in accordance with the principle of subsidiarity. The EU involvement in public health includes legislation and funding on a range of issues such as food, determinants of health, and priority diseases. The EU issues recommendations, legislation and standards to protect people, covering health products and services, and patients' rights in cross-border healthcare. The EU is also active in health promotion and disease prevention and provides information on diseases through the European Centre for Disease Prevention and Control [10].

In this context, the EU level constitutes an important arena for developing policy-oriented research, as public policies affect citizens across borders, in the effort of integrating countries [11]. However, the number and characteristics of BoD studies that consider EU legislation landscape are not known. Therefore, this study aims to systematically analyse BoD studies that address public policies within the EU.

Methods

Search strategy

To identify BoD studies, we carried out a systematic search of six electronic databases: MEDLINE, ScienceDirect, Web of Science, Scopus, EMBASE, and Cochrane. Additionally, two grey literature

registries, OAIster (an open access catalogue) and CABI (a digital library that gathers publications in applied life science), were searched. Articles published between 1 January 1990 and 31 December 2023 were included, accounting for the period since the creation of the BoD metric. The query search was performed on 15 February 2024.

We utilized the following search query across the databases, with adaptations to each search engine: ('European Union' OR 'EU') AND ('legislation' OR 'law' OR 'policy' OR 'policymaking' OR 'regulation' OR 'directive' OR 'recommendation' OR 'decision') OR ('burden of disease' OR 'disease burden' OR 'disability-adjusted life year' OR 'DALY' OR 'YLL' OR 'YLD' OR 'years of life lost' OR 'Years of healthy life lost due to disability' OR 'years lived with disability'). Details regarding search queries are available in the [online supplementary File S1](#).

Inclusion and exclusion criteria

We considered several inclusion criteria: (i) include BoD metrics; (ii) include one or more European countries, or EU-level research; (iii) elaborate or describe a European policy, including but not limited to programme, decision, strategy, directive, regulation, or communication. We included studies written only in English or French, for which abstract and full text were available. The exclusion of inaccessible full texts and duplicates was carried out during the first round for the grey literature, and after the title screening phase, for the six databases.

We used the following exclusion criteria, based on the study design: conference abstracts and opinion papers; papers with no disaggregation to the EU-level or any individual EU country-level. Studies with another methodology, not including any BoD assessment, were also excluded.

The protocol of this review was registered in PROSPERO (ID: [CRD42024513575](#)).

Selection process

The articles retrieved were analysed independently by two authors (JC and DG), following the PRISMA Checklist [12] available in the [online supplementary File S2](#).

The screening phase included two main stages: title and abstract, and full-text. For the title and abstract screening phase, the possible classifications for the studies were: 'Yes', 'Unclear', and 'No'. If the paper was classified as 'No' by both researchers, the paper was removed from the database. If the paper received an 'Unclear' or 'Yes' rating, it progressed to the next phase of selection. An intermediate phase verified the existence of full text.

When there were disagreements between the reviewers in independent assessments, these were discussed in a specific meeting, with consensus reached through reconciliation meetings.

This step evaluated the presence of the inclusion criteria, with further discussion in case the criteria were not fulfilled, leading to the exclusion of the respective article.

Data extraction and analysis

The data were extracted independently by two reviewers (JC and DG). The following characteristics were collected: first author; publishing year; study design (ecological, case study, cross-sectional, cohort, among others); unit of analysis: countries, local settings, regional settings, multi-country or EU-level; country of analysis; topic; primary or secondary origin of data; GBD as source of data; population measure: YLL, YLD and/or DALY; type and in-text location of data visualization tools; EU legislation: type and issuing body; phase of policy cycle.

Particularly, the types of EU legislation, as defined by the EU [13], were extracted, including but not limited to regulations, directives, decisions, recommendations, communications, and policy packages.

The issuing body includes the Council of the European Union, the European Commission, and the European Parliament.

For the policy cycle phase which the paper contributed to, seven stages were defined: issue identification and definition; data, research, and analysis; policy formulation; consultation; policy adoption; policy implementation; policy monitoring and evaluation [14].

Moreover, the location within the full text where the EU legislation is mentioned was analysed, as well as whether any discussion on the potential implications for the EU legislation is discussed. A textual analysis of the discussion verified the link to EU legislation in the articles and the exact recommendations and implications. Word frequency analysis was further employed, considering the following thresholds: 2–4 mentions, 5–10 mentions, and 11–20 mentions. These were reported as descriptive statistics and as visualizations. The following R packages were used: *Officer*, *tm*, *dplyr*, and *ggplot2*. Additionally, a citation analysis was carried out for specific EU policy documents, where the selected articles were referenced, using *Overton* [15].

Data visualization was also analysed, as it serves as a tool to support KT [16] and may increase the likelihood of policy uptake. All results were presented using a descriptive approach.

CADIMA [17] was utilized for general management of the screening process and Microsoft Excel and R v.4.1.3 for data extraction and analysis.

Quality assessment

As there are no standardized quality assessment tools for BoD studies, an adapted version of the quality assessment of ecological studies created by Dufault *et al.* was utilized [18]. This tool classifies the quality of studies according to study design, statistical methodology, and quality of reporting. In total, each article could present a maximum of 21 points. The articles were then ranked in four categories:

- High quality: 18 to 21 points;
- medium quality: 14 to 17 points;
- sufficient quality: 10 to 13 points;
- low quality: <10 points.

The full description of the quality assessment tool can be found in [online supplementary File S2](#).

Results

Descriptive results

Out of the 2054 records screened, 1178 articles were eligible for full-text analysis. For the final selection, we included 83 studies.

Details about the screening process can be found in the PRISMA flow diagram (Fig. 1), while the full list of studies can be found in the [online supplementary File S3](#).

Out of the extracted papers, only 38 had a primary aim of conducting BoD studies. Forty-four were case studies. The units of analyses used were countries ($n = 26$), local settings ($n = 16$), regional settings ($n = 7$), followed by transnational or EU-level papers ($n = 34$). Eighty studies used secondary data, out of which only 37 used GBD data. The most used population measure was DALY, with 53 studies reporting only DALY, 16 together with YLL and YLD, and 2 together with YLL.

The most frequent topic mentioned in the study's aim section was environment ($n = 34$), followed by transport ($n = 10$), infectious diseases ($n = 9$), and food safety ($n = 6$). More details are available in [online supplementary Tables S2 and S3](#).

The temporal pattern of the published BoD studies (Fig. 2) showed a progressive increase in terms of quantity, as the number of articles has increased from one (2004) to a peak of 13 (2020).

The most frequent type of the EU legislation mentioned in the articles was the directive ($n = 47$), regulation ($n = 17$),

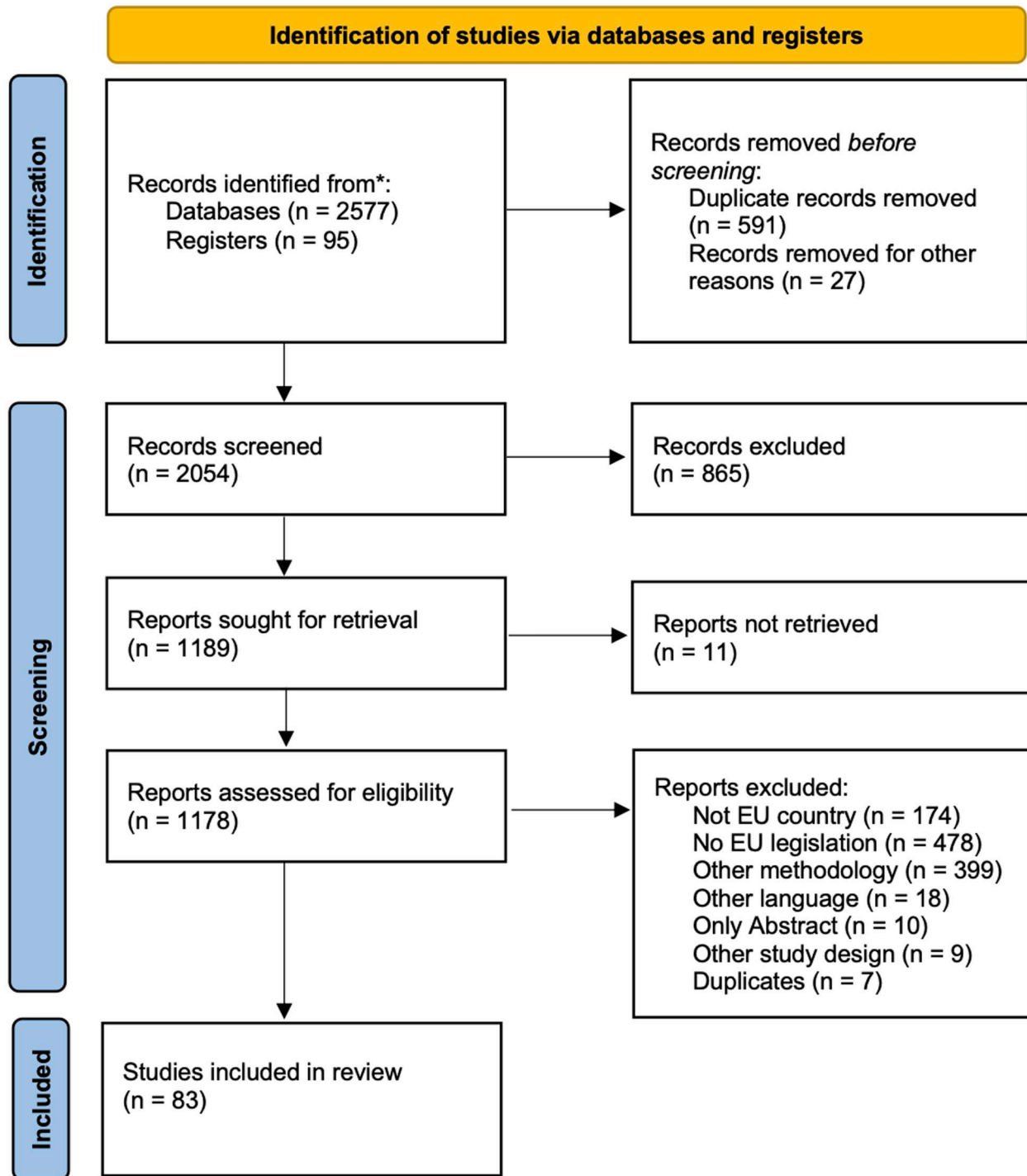


Figure 1. PRISMA flow diagram.

communication ($n = 11$), and decision ($n = 9$). Most of the legislation referenced was issued concomitantly by the European Parliament and the Council of the Union ($n = 53$), followed by the European Commission ($n = 45$). More details can be found in online [supplementary Table S4](#).

When analysing the location within the full text of the EU legislation (Table 1), most articles mention it in multiple places. The introduction ($n = 48$, 27.3%) and methods ($n = 47$, 26.7%) sections were the most frequent places, followed by discussion ($n = 35$, 19.9%). Out of the studies included, 40 presented EU policies in either the conclusion or discussion. In three papers, EU legislation was reflected in all sections of the article, whereas 34 presented EU legislation in just one section.

An analysis of the EU policy implications showed that most papers ($n = 46$, 55.4%) presented a discussion regarding any of the policy cycle stages of the legislation. From these, 28 (60.9%) presented specific policy solutions.

In only one study, the mentioned EU law was in the consultation stage, while three studies contributed directly with information for the data, research, and analysis stage. In 61 studies (74%), the studies provided information, which is valuable for policy evaluation. In 13 (16%), the studies specified contributions for the formulation stage. Finally, the implementation stage was identified in five studies (6%).

Regarding the role of policy use, 49 articles used policies as examples in the introduction, methods, or discussion, while in 43 articles the policies were linked to the study in any article sections. From

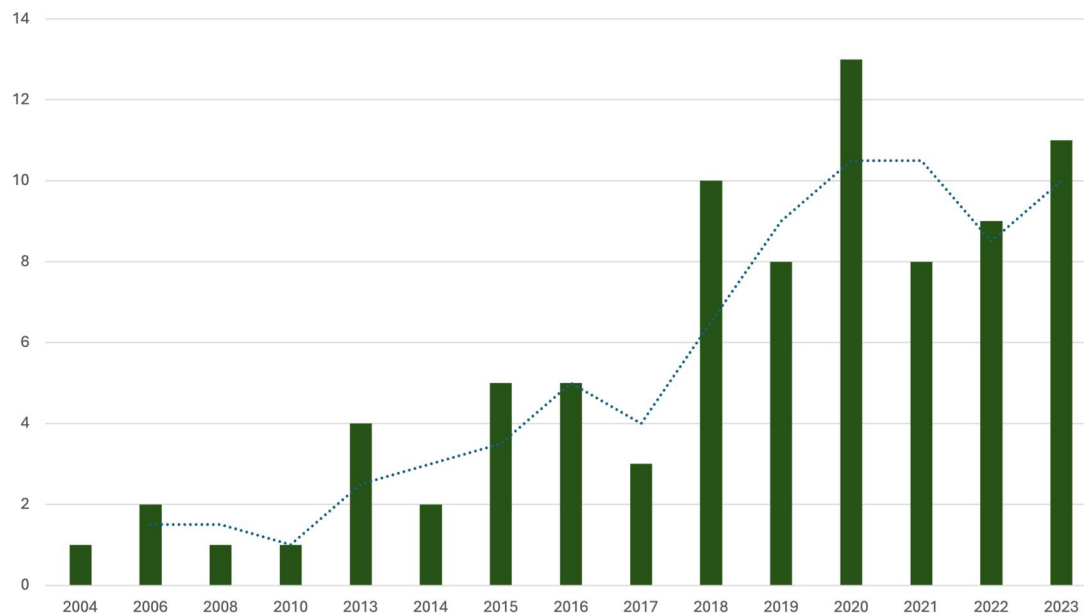


Figure 2. Distribution of burden of disease articles considering EU legislation across publication year.

Table 1. Characteristics of the included studies

EU legislation	Frequency	Percentage (%)
Location in-text		
Abstract	9	5.1
Introduction	48	27.3
Methods	47	26.7
Results	21	11.9
Discussion	35	19.9
Conclusion	214	8.0
NA	2	1.1
Total	176	100
Direct policy implications		
Yes	46	55.4
No	35	42.2
NA	2	2.4
Total	83	100
Role of policy use		
Main results related to policy	8	7.8
Policy linked in other sections	43	42.2
Example	49	48.0
NA	2	2.0
Total	102	100

these, only 8 reported main results related to EU legislation. Fifty-three articles had single use of EU policy (for either examples or policies), 10 presented both uses, and the remaining had multiple entries for policy use.

The word frequency analysis showed that 142 words were mentioned 2–4 times, 14 words between 5 and 10 times, one word between 11 and 20 times. Overall, the most frequent word was ‘health’ (Fig. 3). A word cloud with the 50 most frequent words is available in online [supplementary Fig. S1](#).

The textual analysis of the policy implications showed a great focus on environmental issues, with main recommendations proposing emission limits for air pollution from vehicles, buildings, and wood combustion, as well as limiting exposure to noise, mycotoxins and chemicals in food and water, animal feed products and occupational contexts. In the health sector, the development of specific programmes or funding on tobacco control, cancer, nutrition, and mental health were proposed. Overall, recommendations require a cross-sectoral approach and integration of knowledge in policies.

Based on the query performed in Overton, only 42 articles (50.6%) have been cited at the European level, in a total of 129

policies out of all 401 policy citations. Sixty percent of the European policies ($n = 86$), for 18 of the studies included in our review, are citations by EU institutions. From these, 16 were issued by supporting research services. Around 67.4% ($n = 58$) were cited by EUR-Lex. Additional results are provided in online [supplementary Tables S5–S7](#).

In terms of distribution of data visualization usage by article section, different studies presented several elements in the following sections: Results section ($n = 65$), methods ($n = 21$), discussion ($n = 13$), abstract ($n = 10$), supplementary ($n = 8$), and introduction ($n = 5$). Seven studies did not present any data visualisation element. The most common elements were bar plots ($n = 54$), diagrams ($n = 35$), and maps ($n = 24$). More details are presented in the online [supplementary Table S8](#).

Quality appraisal

The total scores ranged between 11 and 21 points. The scores were then disaggregated by characteristics: for study design, the scores ranged between 5 and 12 points; for statistical methodology, the scores ranged between 1 and 6 points; and for quality of reporting, the scores ranged between 2 ($n = 35$) and 3 ($n = 48$). Based on the overall rating of the quality thresholds, 26.2% articles were of high quality, 54.7% of medium quality, and 19.1% of sufficient quality. Detailed scoring can be found in online [supplementary Table S9](#).

Discussion

This study summarized BoD studies, which addressed European legislation in its research. The number of BoD studies has been increasing throughout the years. Eight or more studies have been published per year between 2018 and 2023. This represents around 15% of all BoD studies conducted in Europe, denoting a low impact of the legal contextualization or policy implications in the BoD studies.

The retrieved articles showed that DALY was the most used population health measure (either alone, or in combination with YLL and/or YLD). Most mapped metrics have been computed using secondary data sources. There are publicly available databases that can be employed in calculating DALYs at multiple levels (either local, national, or regional) or can provide already calculated estimates, useful for policymakers and patients alike in advocacy, setting priorities, and guiding planning and financing, efforts [19, 20].

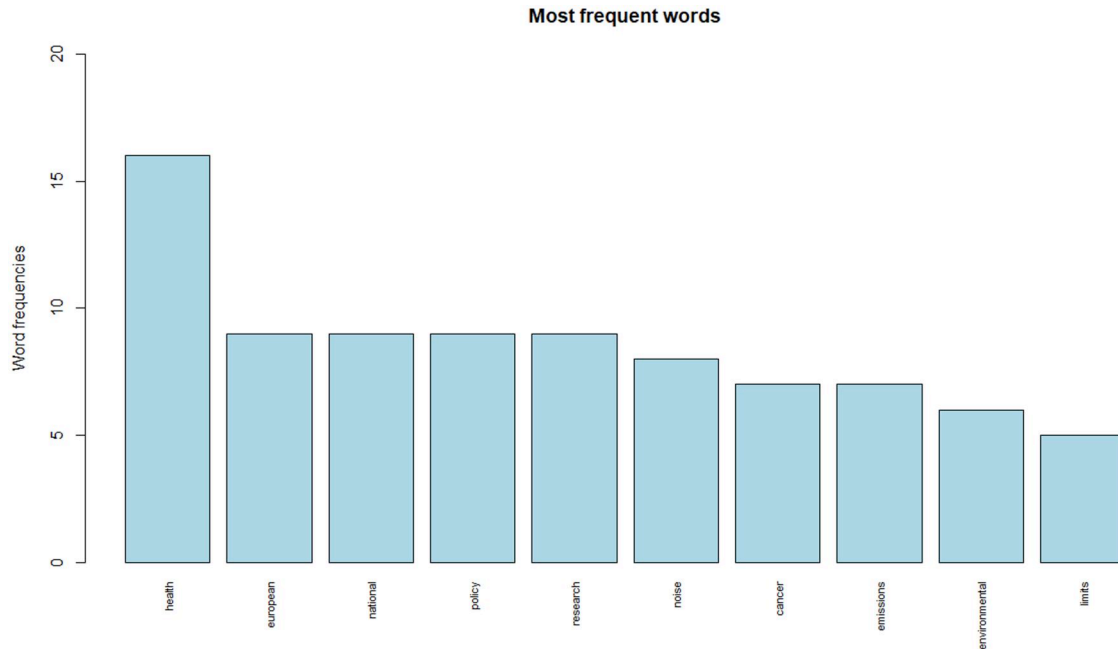


Figure 3. Word frequency analysis in the retrieved policy implications from the articles.

One of the most used sources, the GBD, has been providing estimates for a high number of diseases, injuries, and risk factors, for different geographical units. Since 1990, the GBD study has suffered transformations in various aspects, such as improvement of data sources and analytical approaches [3]. In order to strengthen efforts of providing timely estimates and support policymakers (and implicitly, to familiarize them with the BoD metrics), WHO and IHME have signed two memoranda of understanding, the latest in 2022 [21].

Other countries, such as Germany, Belgium, Estonia, or the Netherlands have computed their own estimates using national data [22–25]. However, several barriers were reported when undertaking this effort, such as health system fragmentation, data quality or availability of different types of resources, which would hinder efforts aiming at calculating burden of disease metrics [26, 27]. Within the literature, there have been published guidelines on DALY computation, either overall [28] or focusing on a certain disease [29].

The study objectives of the articles revolved around environment, transport, and infectious diseases, accounting for climate changes and its domino effects [30, 31] as well as mitigation and adaptation through urban planning [32] highlighting the interconnection of health across different disciplines.

The study found that articles most often include legislation in the introduction, methods, and discussion sections, which may suggest the significance of the research findings in informing or influencing policy decisions. The abstract, as it summarizes the information, might be a starting point for policymakers, together with discussion, conclusions and any graphical element that systematizes information. This is of utmost importance as policymakers have very short timeframes for consulting and using evidence, being useful to use key elements in research to aid translation to policy [9]. Moreover, science-policy interfaces are useful to bridge this gap, improving evidence delivery in a direct and simple manner to policymakers [33].

The analysis of policy implications allowed to understand the most common suggestions made by researchers, with most articles including the following words: Health, European, national, policy, and research. This suggests a major focus on health, with emphasis on the translation of European policies into national law, as well as the central role of research in providing evidence-based information. The forward citation analysis of the articles in policy documents

showed that over half of studies were used in policy papers within the EU, with most being published in the EU's Publications Office, EUR-Lex. An analysis of Overton showed that across all subject areas, only about 5% of articles are cited in policy, with Social Sciences and Humanities being the most cited in policy documents, followed by Health Sciences [15]. This information is important for policy implementation and evaluation of impact, striving to improve the bridge between research and policymaking.

In translating scientific knowledge into policymaking, data visualization has proved invaluable in increasing comprehension and engaging stakeholders within the policy cycle [34]. This review showed that most of the included articles used various types of data visualization tools, with bar plots, diagrams, maps, and line plots being most often employed to summarize and communicate in a graphical manner in the selected articles. Studies have emphasized the importance of data visualization in engaging different actors involved in the policy cycle, as it facilitates making sense of large datasets; however, policymakers should be trained in properly interpreting data visualization employed in communicating results that could be used in policies [16]. Moreover, researchers can direct their research to improve KT. For instance, governments or other authorities could mandate, and eventually support, updated estimates that could provide a realistic picture of the population health [35].

A recent study interviewed policy officers and reported that the main issue in BoD translation is the lack of knowledge on BoD and its complexity [34], requiring directed efforts to disseminate and inform policymakers about BoD metrics, including better multisectorial communication among all the stakeholders involved in data collection, acquisition, analysis, and visualization as well as improvement of data communication efforts as areas of improvement for knowledge translation.

This review complements the existing reviews on BoD studies that have selected articles on risk factors, infectious diseases, rare chronic noncommunicable diseases, methodological choices in estimating injuries, or noncommunicable diseases [2, 26].

Research and policy implications

This study showed the need for a policy contextualization of BoD studies, as these may provide insights on background, methodology, or policy implications. However, EU laws might originate some

questions about its implications among researchers and legislators, which might require further guidance on its implementation on the national level.

Moreover, researchers can direct their research to improve its knowledge translation. For instance, governmental authorities could mandate, and eventually support, updated estimates that could provide a realistic picture of the population health within a country, as it is the case of the burden of foodborne disease in the Netherlands, an example of good practice of science to policy translation [35].

The emergence of new means of communication and the unprecedented rate at which data can be shared are inevitably linked to the acceleration of the transfer of knowledge on BoD. As such, it is important to invest in effective science communication of the usefulness of BoD, enabling policymakers to understand complex scientific concepts, assess risks, and develop policies that align with scientific findings [36]. However, researchers currently lack or have limited knowledge in BoD KT [27]. Adequate communication incentives and training of researchers are key facilitators to embed research into policy [37].

In spite of these factors, the translation from science to policy is not straightforward. Even when policymakers have access to scientific knowledge, BoD will not necessarily be considered and used for prioritization and resource allocation [38]. Thus, it is important for researchers to be aware of the political context and evolution of policies, allowing to encounter windows of opportunity to advocate for including BoD results into the policy cycle [39].

Limitations

One of the limitations of this review is represented by the search strategy. Considering that a general terminology was employed and have not delved into specific health subtopics, related to specific diseases and risk factors, this might influence the number of records obtained. Furthermore, the use of specific BoD terms might limit the studies retrieved, as other terms, such as population attributable fraction, and population impact fraction, might also be employed in BoD studies bridging with EU legislation. Another limitation is the language consideration, which might exclude other relevant BoD papers.

As this study did not focus on governmental websites and reports, some BoD assessments might not have been retrieved; however, further studies are required to confirm this.

Conclusion

This study presents BoD studies that consider EU legislation, which accounts for about 15% of all BoD studies carried out in Europe. The findings of this review indicate a poor consideration of the legal and policy changes, despite growing efforts to include EU legislation considerations into BoD research. Increased efforts to focus research on a particular policy implementation and effectiveness evaluations could make the results more beneficial and applicable to the EU policy cycle.

Future research should focus on KT efforts, as well as improving BoD studies using a policy-oriented perspective to improve its uptake by policymakers.

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Supplementary data

[Supplementary data](#) are available at *EURPUB* online.

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Key points

- Burden of disease studies which consider EU legislation account for only 15% of all European burden of disease studies.
- Out of the included studies, only eight report the use of burden of disease metrics in evaluation of EU policies.
- Efforts are required to increase the policy uptake in the EU, including improving the policy focus in research, as well as conducting effectiveness evaluation studies.

Data availability

Data are available in the [Supplementary Material](#) and available upon request to the corresponding author.

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