



The role of burden of disease estimates in European Union Health policymaking: A systematic analysis of EU legislation

José Chen-Xu^{a,b,*}, Diana Grad^c, Nour Mahrouseh^d, João Vasco Santos^{e,f}, Silvia Riva^g, Federica Gazzelloni^h, Brigid Unimⁱ, Periklis Charalampous^j, Enkeleint A. Mechili^{k,l}, Sarah Cuschieri^m, Vanessa Gorassoⁿ, Henk Hilderink^o, Orsolya Varga^{d,p}, Susana Viegas^a

^a NOVA National School of Public Health, Public Health Research Centre, Comprehensive Health Research Center, CHRC, REAL, CCAL, NOVA University Lisbon, Lisbon, Portugal

^b Public Health Unit, Local Health Unit Baixo Mondego, Figueira da Foz, Portugal

^c Department of Public Health, Faculty of Political, Administrative and Communication Sciences, Babeş-Bolyai University, Cluj-Napoca, Romania

^d Department of Public Health and Epidemiology, Faculty of Medicine, University of Debrecen, Hungary

^e Public Health Unit, Local Health Unit Santo António, Porto, Portugal

^f CINTESIS@RISE, MEDCIDS, Faculty of Medicine of the University of Porto, Porto, Portugal

^g School of Allied Health, and Life Sciences, St Mary's University, Twickenham, London, UK

^h Independent Researcher, Rome, Italy

ⁱ Department of Cardiovascular, Endocrine-metabolic Diseases and Aging, Italian National Institute of Health, Rome, Italy

^j Department of Public Health, Erasmus MC, University Medical Center Rotterdam, Rotterdam, the Netherlands

^k Department of Healthcare, Faculty of Health, University of Vlora, Vlora, Albania

^l School of Medicine, University of Crete, Crete, Greece

^m Faculty of Medicine & Surgery, University of Malta, Msida, Malta

ⁿ Public health and epidemiology, Sciensano, Brussels, Belgium

^o Health Knowledge Integration, Dutch National Institute for Public Health and the Environment, Bilthoven, the Netherlands

^p Syreon Research Institute, Budapest, Hungary

ARTICLE INFO

Keywords:

European Union
EU legislation
Policymaking
Burden of disease
Knowledge translation

ABSTRACT

Background: The use of burden of disease (BoD) metrics in policymaking is crucial for evidence-based decision-making. However, there is currently no information available regarding their utilisation in policies at the European level.

Objective: This study aimed to analyse the use of BoD metrics within the European legislation.

Methods: Systematic searches on EUR-Lex were conducted for documents published between 2004 and 2023, to account for European Union-25 (EU-25). Network and qualitative analyses of documents were conducted to assess the legislation content.

Results: In total, 2615 documents were found, of which 191 included BoD metrics. Among the selected documents, 131 (69 %) were published after 2018. Ten were legally binding documents. The most prevalent EuroVoc (EU's multilingual and multidisciplinary thesaurus) domains were social questions and environment. The most frequent EuroVoc terms were climate change policy ($n = 45$), EU environmental policy ($n = 32$) and pollution control measures ($n = 32$). The most common EU institution responsible for the retrieved documents was the European Commission ($n = 152$). As for the purposes of usage, argument ($n = 93$) and impact assessment ($n = 50$) were most common. Most BoD metrics were localized in the main text ($n = 122$).

Conclusion: Despite growing recognition of BoD metrics in supporting policymaking, their use remains focused on environmental health topics. Further efforts in training policymakers, knowledge dissemination and policy-oriented research could enhance the uptake of BoD studies in EU policies.

* Corresponding author at: National School of Public Health, NOVA University of Lisbon, Avenida Padre Cruz, 1600-560, Lisbon, Portugal.

E-mail address: josechenx@gmail.com (J. Chen-Xu).

<https://doi.org/10.1016/j.healthpol.2025.105387>

Received 3 June 2024; Received in revised form 27 May 2025; Accepted 26 June 2025

Available online 27 June 2025

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Background

Public policies are often defined as a “set of interrelated decisions taken by a political actor or a group considering the goals and means available” [1]. These operate at various levels, from local to supra-national, and in several areas, with the European Union (EU) possessing public health competences delegated by Member States through the Treaty on the Functioning of the EU (Article 168 TFEU, 1958). While adhering to the principles of subsidiarity and proportionality, the EU aims to address areas where national governments may lack effective response, with the aim of contributing to improving the population’s health status [2]. This was more apparent after the Covid-19 pandemic, with the emergence of the vision of a European Health Union [3].

In this context, the role of scientific evidence in guiding policy-making has become increasingly important, particularly as the EU seeks to create effective, equitable, and sustainable public policies across diverse Member States. Evidence-informed decision-making is the process of “locating, evaluating, and coordinating the available data to support policies and initiatives” [4]. Whenever possible, public policies across different sectors should be based on the best scientific evidence, best practices, and ethical considerations. These factors contribute to the sustainability, equity and justice of public policies, and ultimately favourable outcomes for EU citizens [5].

Burden of disease (BoD) studies quantify the health impact of diseases and risk factors, by utilising comprehensive metrics, most notably disability-adjusted life years (DALY). A DALY is a measure of health burden which quantifies the impact of diseases and conditions on a population. Two indicators are combined to determine DALYs: the years of life lost due to premature mortality (YLL), and the years lost due to disability (YLD) [6,7]. Publicly available estimates for these summary measures of population health are provided by the Global Burden of Disease (GBD) studies and the World Health Organization (WHO) [7,8], with some results particularly directed to EU Member States [9], and various countries that conduct national BoD studies [10–12].

DALY is useful for evidence-based public health policy, particularly in the baseline assessment, evaluation and definition of health system targets [13]. Its contribution to policy formulation across sectors allows to quantify potential health co-benefits - that is the case of the improvement of vehicle emission standards and the respective decrease of NOx emissions [14]. It can be used to measure direct and indirect effects of policies from various health domains [15–17], such as modelling benefits of climate policies [18]. BoD provides comprehensive measures of the impact of health problems on populations and can be used to inform priority setting, resource allocation and policy appraisal. It also allows to direct efforts towards vulnerable populations [19–21]. Despite this potential, many policymakers and stakeholders lack awareness of BoD’s importance and practical utility. In addition, coordination between research producers and policy users remains weak, hindering the effective translation of these metrics into actionable policies [22].

However, it is unclear how BoD metrics are being used in European public policies since there is no monitoring or evaluation of the metrics’ application in the European legislation. At the same time, the utilisation of BoD metrics appears to be gaining visibility in public health discourse and policy contexts—including in EU initiatives related to cancer prevention [23] and food systems [24]. These developments point to a growing, though still uneven, integration of BoD evidence in policymaking.

Driven by the fact that the utilisation of BoD metrics has become increasingly prominent in health policymaking, we aimed to provide a systematic overview of legislations present in EUR-Lex that utilise BoD metrics in the EU. To the best of our knowledge, this is the first study that provides an in-depth analysis of knowledge translation of BoD within European policies. This study systematically reviews EU legislation to assess how, where, and for what purposes BoD metrics are being

integrated into policymaking.

Methods

Search strategy and eligibility criteria

Two reviewers (JC and DG) independently searched EUR-Lex which includes all European laws and other legal documents. EUR-Lex provides free access, in the 24 official EU languages, to the Official Journal of the EU, as well as EU laws, preparatory acts, case-laws, international agreements, summaries of legislation, and other public documents [25].

The search included documents published between January 1, 2004 and December 31, 2023 to identify EU legislation that includes any reference to BoD concepts, namely DALY, YLL and YLD. This period included the adherence of ten countries to the EU in 2004 (EU-25).

The search items were defined as follows: “disability-adjusted life year*”; “DALY*”; “YLL”; “YOLL”; “YLD”; “years of life lost”; “years lost due to disability”; “years lived with disability”. These were individually searched in EUR-Lex to retrieve all possible documents that might include BoD metrics.

Several types of legislative documents are produced within the EU, which can be binding or non-binding. The following inclusion criteria were considered: published legislation documents (available in EUR-Lex) and dated 2004 onwards. In terms of documents to be included, we considered binding documents (regulation; directive; decision; or treaty), and non-binding legislations: resolutions, guidelines, communications, opinions, preparatory documents, reports, including proposals and amendments, as well as working documents, as these might indicate the inclusion of BoD indicators in policy proposals and serve as supporting documents for the aforementioned binding law.

The absence of BoD metrics and the type of documents were considered as exclusion criteria, namely: minutes, verbatim report of proceedings, EU case-law, such as judgement or High Court documents, authorisations, written questions, informations, and other non-relevant documents were excluded. No language restrictions were applied. A description of the main types of legislation is available in Table S1. All conflicts were resolved “via consensus”, more specifically, through discussion and re-review until agreement.

Data collection and analysis

Legislative files were screened independently by three authors (JC, DG and NM), in line with the criteria mentioned above. Disagreements between reviewers in independent assessments were resolved by a consensus meeting. For the screening process, we used PRISMA guidelines (Fig. 1) [26].

For data analysis, an extraction sheet in Microsoft Excel was used, with a pre-determined list of information. This list included: type of document, publication date, subject classification, author and target groups. The target groups to which legislation was aimed at were classified as: Academia, Children, Community, Disabled persons, Elderly, General Governments, Organisations, Pregnant women, and Working population [27]. Additionally, we extracted information about the BoD metrics’ text location within the legislation, as well as the existence of bibliographic references, and the type of usage (as a definition, a methodology, an example, setting goal/indicator, argument, evaluation, and impact assessment). EuroVoc descriptor was also extracted where applicable. EuroVoc represents “EU’s multilingual and multidisciplinary thesaurus. Its keywords are organized in 21 domains and 127 sub-domains”, used to describe the content of documents in EUR-Lex [28]. More details about the EuroVoc domains included in our paper are available in the Supplementary Material.

Legislative documents have EuroVoc descriptors assigned, which serves as a basis to assign the theme. However, for the ones that did not present descriptors, we analysed the content of legislative texts using an inductive approach, by agreement between the three reviewers, in order

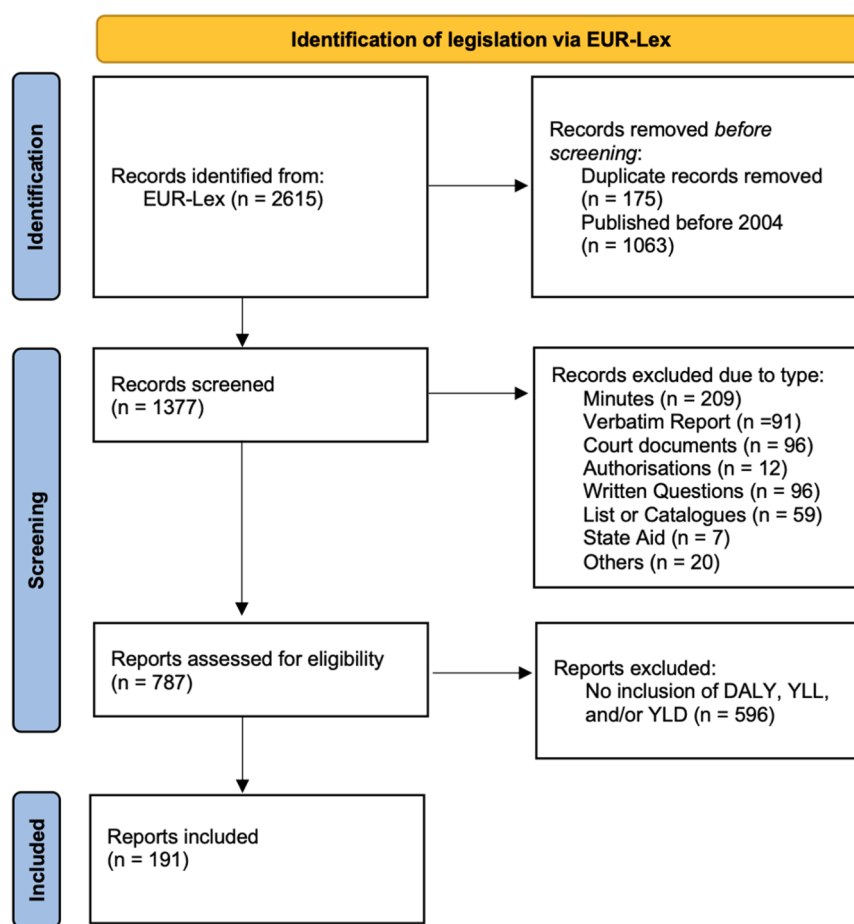


Fig. 1. PRISMA flowchart of the search strategy and selection of records in EUR-Lex containing burden of disease metrics, from 2004 to 2023.

to create themes. Each researcher coded legislations into one or more of the theme categories. For the qualitative analysis, the following codes were grouped under themes: “Disease and, or risk factors to be prevented” (codes: “communicable diseases”, “NCDs”, “risk factors”), “Disease burden measure” (codes: “DALY”, “YLD”, “YLL”), and “Definition”. These were used to evaluate the landscape of diseases and associated risk factors targeted for prevention, while excluding injuries and accidental deaths. A randomly selected sample of 50 % of legislative texts was subjected to coding by two coders (DG and NM). After establishing satisfactory reliability with the Cohen’s Kappa (k) measure, DG independently proceeded to code the remaining data [29]. The Kappa statistics evaluates the consistency between two classifiers categorising terms into policy-relevant categories. According to Cohen, the Kappa scores should be interpreted as follows: values 0.01–0.20 indicate no or little agreement, values 0.21–0.40 indicate fair agreement, values 0.41–0.60 indicate moderate agreement, values 0.61–0.80 indicate substantial agreement, and values 0.81–1.00 indicate nearly perfect agreement Kappa coefficient [30]. To complement the content analysis, network analysis using cluster structure was carried out to represent domains and subdomains of EuroVoc terms where we connected subdomains with their original domains and other domains where these terms were present. To our knowledge, network analysis of EuroVoc descriptors specifically focused on BoD terminology within EU legislative texts has not been previously conducted. While EuroVoc-based analyses have been applied in the context of legal text classification and semantic mapping of EU documents [31], this study uniquely applies network metrics and visualizations to uncover how BoD-related concepts are structurally embedded across policy domains. This approach extends previous research by linking public health terminology with environmental and social policy clusters, offering new insights

into the cross-sectoral framing of health within EU legislation.

The visualisation of the analysis was conducted using Gephi v.0.10.1 [32] to produce a cluster network analysis, whereas NVivo v.14 [33] was used for a qualitative data analysis.

Results

Description of identified legislation

Our search strategies retrieved 2615 documents (Fig. 1) and, after removing duplicates and irrelevant document types, we screened 1377 documents. From these, we analysed 787 for BoD metrics, which resulted in 191 documents (24.2 % of screened documents). The complete list of legislative files is available in Table S2.

The distributions of types of documents ranged between 76 % (working documents, $n = 145$) to 1 % (reports, $n = 3$).

The use of BoD metrics greatly increased in the most recent years (Figures S1–S3), with most documents published in 2022 ($n = 44$; 23 %). The majority ($n = 131$; 69 %) were published after 2018.

Of the included documents, ten (5 %) were legally binding documents, out of which six (3 %) were still in force. The remaining 95 % were non-binding, most notably “Working Documents”.

A review of the main responsible body revealed that most (80 %) were issued by the European Commission, followed by joint documents by the Council of the EU and the European Commission, which constituted around 12 % of the EU legislation. More information regarding the remaining responsible entities is available in Table S3.

From the ones issued by the European Commission ($n = 179$), the Directorate-General (DG) of Environment was responsible for 39 (22 %), followed by 24 (13 %) of the Secretariat-General, 17 (10 %) of the DG

Agriculture, and 16 (9 %) of the DG Health and Food Safety.

In terms of target group (Table 1), some documents presented several groups. The most common were governmental bodies ($n = 87$, 38.0 %), followed by organisations ($n = 55$, 24.0 %) and general public ($n = 52$, 22.7 %).

Regarding EuroVoc terms, 152 documents had EuroVoc terms (subdomains) assigned to them and these included a total of 1348 terms, out of which 376 were unique terms which are associated with the 20 EuroVoc domains (Table S4). The most frequent EuroVoc terms were “climate change policy” ($n = 45$), “EU environmental policy” ($n = 32$) and “pollution control measures” ($n = 32$). The most prevalent domains were “social questions” and “environment”. A full network map is available in Figure S4, and the specific map for the environment domain is shown in Figure S5.

Furthermore, we performed a network analysis of the connection between EuroVoc terms. The network analysis included 376 nodes (unique terms) and 5547 edges (connections), based on which 46 nodes (unique terms) were repeated >50 times among retrieved policies (Fig. 2). The most repeated nodes (EuroVoc terms) which had the highest connections with other terms were climate change policy ($n = 405$), EU environmental policy ($n = 286$), pollution control measures ($n = 278$) and application of EU law ($n = 270$) repeated. The high connectivity of environmental terms with BoD-related descriptors suggests a legislative trend toward recognizing the health impacts of environmental exposures, aligning with recent WHO and EU policy shifts. A full analysis of the network patterns from EuroVoc terms with ten connections or more is available in the Supplementary Figure S6.

BoD metrics were used to support policies, mostly by providing an argument in favour ($n = 93$, 42 %), followed by impact assessment ($n = 50$, 23 %) and setting goal/indicator ($n = 20$, 9.3 %). The full information about the different uses of BoD metrics is available in Table S5.

The location where BoD was detected also varied. Most legislative documents presented BoD metrics in the main text of non-binding documents ($n = 122$, 54 %), annex ($n = 48$, 21 %) and reference ($n = 36$, 16 %). Information about other references to BoD metrics can be found in Table S6. To note that, out of the included files, only 12 documents referenced peer-reviewed scientific studies.

Out of the documents analysed, 107 presented references. The most common referred sources were EU sources or third-party studies commissioned by the EU ($n = 66$), the WHO ($n = 23$), and BoD studies ($n = 12$). GBD was only referenced twice.

Qualitative analysis

Fourteen themes have emerged from the legislation content (Fig. 3). The most frequent one was environmental legislation (31 %) followed by 10.5 % of reform policies and occupational policies (9.9 %). The least prevalent themes were funding (1.6 %) and health strategies (2.1 %), as shown in Table S7.

Qualitative results were disaggregated around the codes and

respective themes. The number of mentions associated with each code ranged from 11 (YLD) to 224 (DALY), as shown in Table S8. Most codes presented Cohen kappa results (Table S9) higher than 0.61, indicating substantial (0.61–0.80) or perfect agreement (0.81–1.00), except for the risk factor code, which presented a fair agreement of 0.39.

Regarding the coded text for “communicable diseases”, the following example illustrates the legislation analysed:

“Infectious diseases (e.g. HIV/AIDS, tuberculosis and malaria), are a global concern, accounting for 41 % of the 1.5 billion disability adjusted life years worldwide, with 8 % of these in Europe” [34].

“Non-communicable diseases” were also evident, specifically in the excerpt:

“In 2005 alone, it was estimated that over 17 million disability-adjusted life-years were lost because of cancer in the WHO European region” [35].

As for “risk factors”, the following section presents an example of its inclusion in EU legislation:

“the health burden (in terms of years of life lost) for other indicators (O_3 , NO_2) is also above the EU average” [36].

When analysing disease burden measures, these were described in several sections, including:

“mental health problems account for almost 40 % of years lived with disability” [37].

“the European Environment Agency point to about 21,500 premature deaths (or 244,800 years of life lost (YLL)) attributable to fine particulate matter” [38].

As for the methodology describing BoD metrics, the following example illustrates its presence in EU legislation:

“The valuation of health impacts was undertaken based on (...) the use of disability adjusted life years (DALYs) and their monetisation” [39].

Discussion

This study aimed to provide a systematic overview of legislations available in EUR-Lex using BoD metrics. To our knowledge, this is the first paper analysing public policies at the EU level that covers knowledge translation on BoD.

BoD metrics and its usability: a complex metric

This study found that only 191 documents (7.3 % of the retrieved ones) of the legislation published in the past 20 years within EUR-Lex mentioned BoD metrics. This relatively low uptake indicates a gap between the growing academic production of BoD data and its translation into actionable legislative language. This may be attributed to several reasons. Initially, the metrics represented a great advancement, as they provided regular estimates consistent with population and life table estimates by the United Nations [40]. Secondly, BoD was notorious for the inclusion of social weighting factors and assumptions made on disability weights and on data from countries where data was scarce. There has been a substantial adaptation and improvement of the methodology across the years, with the increase of available data and national BoD studies [41].

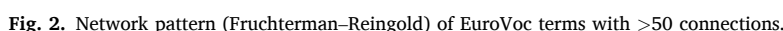
Thirdly, when producing BoD estimates, health system fragmentation, and data quality or availability, can hinder efforts aiming at calculating BoD metrics [42,43]. Above all, BoD metrics comprise a high level of complexity, possibly limiting its use and comprehension [44]. Finally, while most national DALY estimates are traditionally produced by the academia [45], the knowledge transfer to policy processes

Table 1

Target groups of the legislation containing burden of disease metrics, published from 2004 to 2023.

Target Group	N (%)
Governmental bodies	87 (38.0)
Organisations	55 (24.0)
General public	52 (22.7)
Working population	21 (9.2)
Children	6 (2.6)
Community	3 (1.3)
Elderly	2 (0.9)
Disabled persons	1 (0.4)
Academia	1 (0.4)
Pregnant women	1 (0.4)
Total	229

Legend: a legislation can target several groups.



The recently proposed burden of proof can improve the usability of BoD metrics, by providing a policy translation framework for BoD studies [48]. This translates the BoD aspects, including strength of association and robustness of results, into a risk-outcome score and a star rating, respectively [49]. This approach improves knowledge translation by facilitating prioritisation and resource allocation, alongside the

Our study compared the distribution across time, and across policies, finding that the use of BoD metrics in EU legislation significantly increased after 2018. The increase in recent years, especially in 2020 and 2022, might be due to the prompt availability of research results and the use of the methodology at different levels, which was amplified during the pandemic [52], as health was put at the centre of European priorities, as well as EU's focus on realising the Green Deal [53]. The lower quantity in 2021 and 2023 might be explained by the lagging time from the proposal until the final approval of EU legislation. The analysis by topic highlights the intersectionality of health and health metrics, which go beyond specific sectors. This may be due to the “health in all policies” strategy, holding a great potential to effectively improve population health [54]. Moreover, an important aspect is the One Health perspective, connecting health to environment and animal health, as these fields influence and impact each other [55]. Results of the cluster analysis show a clear relation to health determinants, including economical, societal aspects and the most prevalent, environmental topics. These are also part of the EU's priorities to tackle through several

approaches including research initiatives, for example through covering these health determinants and priorities across EU Framework Programmes for research and innovation [56]. Our qualitative analysis confirmed that environmental legislation is the most common theme, followed by reform and occupational policies, which aligns with the EU's broader agenda on sustainability and labor health.

Most retrieved documents were non-binding, particularly in environmental and public health domains, reflecting the EU's preference for soft law instruments in areas where legislative competence is shared or limited. There are exceptions to this, which includes several binding legislations, especially in the area of trade, environment, health and several other aspects [2], which aim at fulfilling EU's mission and tackle areas where member states do not have resources or are not able to accomplish alone. In health policy, the focus remains mainly in financing and regulation [57]. While these policies exert influence on the legal framework, the crucial question remains regarding the extent of their impact and its final applicability. This finding is also underscored by a published paper assessing preventive diabetes mellitus legislation on the EU level, which uncovered that a substantial portion of health-related policies were non-binding soft laws [58]. This finding suggests that a deeper examination on the efficiency and reach of such measures within the legislative framework is required.

The main target group for the retrieved legislations were governments, suggesting that a harmonised approach across the EU member countries has been one of the main aims, in line with the Article 168 of the TFEU [2]. As for the responsible EU organizations that issued the analysed legislations, the European Commission has overseen many the included documents. This is in line with the legislative function of this body [2], showing that translation of BoD findings is happening fairly in "Working Documents" produced by the teams of the different European Commission's Directorates. However, knowledge translation, the link of knowledge production stakeholders (academia), and knowledge utilization stakeholders (policymakers) [59], is still lagging behind, with less than a quarter of all legislative files considered in this review.

When analysing the legislative files' content, most terms were located in the main text followed by annex and references. However, the difference is high, with >2.5 and 3.4 times respectively BoD terms being mentioned in the main text as compared to the annex or references. Their usage in the main text might suggest a greater familiarity with the BoD methodology. Indeed, the inclusion of BoD metrics in legislation marks a significant stride forward. It demonstrates a shift from merely focusing on rates and mortality to incorporating comprehensive indicators such as DALY, YLL, and YLD. The predominance of DALY, with fewer mentions of YLL or YLD, also points to a preference for composite metrics that summarize total disease burden over more specific sub-components. This holistic perspective is essential for policies that effectively address health challenges and allocate resources where they are most needed. The qualitative analysis showed that risk factors were the most frequent area to be tackled by the policy, whereas DALY was the most frequent BoD metric. Since re-endorsement by the WHO, DALY has been utilized in numerous studies to be used to quantify environmental BoD in addition to YLL, which are gaining popularity and justify their use in environmental legislation [60,61]. This also may be due to the EU's legislative shift towards preventive policies, particularly targeting risk factors to prevent non-communicable diseases [62]. Oliveira et al. analysed the national health plans and official government web pages for 145 countries to assess whether the DALY estimates produced by the GBD study were aligned with the priorities listed in national health plans. From the GBD study list of the 20 most burdensome conditions (per country) only 46 % corresponded with diseases listed as health priorities [63].

Communicable diseases were not the main focus of EU legislations before the onset of COVID-19 in 2019 and not as comprehensive: only 12 legislative files referenced BoD studies. At the same time, some of the most prevalent themes were related to the environment, followed by reform efforts and occupational health. For instance, environmental risk

factors have direct effects on health, emphasizing that the EU becomes more active in policies pertaining to this domain and that environmental risk factors are high on the policy agenda [64,65].

Moreover, there has been a noticeable trend in academia and among stakeholders towards increased utilisation of BoD measures in recent years, accompanied by the production of country-specific studies [11, 43,45]. The European Office of the WHO and the Institute for Health Metrics and Evaluation have signed several agreements to produce specific BoD estimates for the region, including national and subnational estimates, as well as forecasting [66,67]. While the implementation may still be flawless, this represents a significant improvement. With funding support for such initiatives, it is likely that these results will be increasingly utilised by policymakers in the years to come. A 2023 report published by the DG Research and Innovation states that the mechanisms and processes for exchanging information between knowledge actors and policymakers to inform policymaking in the EU are evolving. There is a growing recognition of the importance of scientific input in public debates, with governments increasingly inclined to leverage scientific advice mechanisms. This trend highlights the rising prominence of evidence-based decision-making in shaping policies across various sectors within the European context [22]. On the other hand, the low number ($n = 12$) of scientific resources highlights a reliance on institutional or commissioned reports rather than direct academic sources, potentially limiting the diversity of scientific perspectives in policymaking. Furthermore, the importance of data reuse cannot be understated in the EU health policy arena, particularly during the implementation of the European Health Data Space. By facilitating the comparison of national health systems and outcomes across member states, data reuse enhances transparency, accountability, and evidence-based decision-making within the EU. The limited appearance of BoD metrics in references and annexes compared to the main text may suggest that these metrics are often cited for rhetorical support rather than as foundational evidence. This could imply superficial rather than integrative use of BoD findings in policy narratives.

Implications for policymaking and research

Our findings suggest that BoD metrics, particularly DALYs, have been predominantly used in EU environmental and public health policies. By providing a detailed examination of case studies where BoD metrics influenced legislative outcomes, we offer a deeper insight into the potential for these metrics to shape policy decisions in areas such as healthcare funding, disease prevention, and health promotion initiatives. While BoD is seen as a strong metric in many fields, its use is not yet consensual by different stakeholders [42,68]. Coordination and participation of different stakeholders are essential for improving the use of BoD metrics and its translation to policy [22]. This can entail training programs or knowledge exchange platforms, thus bridging the gap between research and policy.

Additionally, the use of health metrics has the potential to expand to other fields, requiring further dissemination efforts and capacity building of policymakers to better use and interpret BoD metrics [44], including research offices of EU institutions, such as the European Parliament Research Service. Specifically, investing in communication of BoD results is relevant for improving the translation into policy [69], including data visualisation tools, which can potentially improve policymakers' understanding of scientific findings [70,71] and improve decision-making quality [72].

Conversely, evidence has a heterogeneous effect in lawmaking [73], as this is highly influenced by political and socioeconomic conditions [74]. As such, evidence-informed policymaking requires greater cooperation between academia and policymaking institutions, as well as openness from policymakers to receive input from academia [75], raising the importance of connecting the science to policy nexus to increase policy-oriented research and its uptake in EU policy. Researchers currently lack or have limited knowledge in BoD knowledge translation,

which may hinder efforts in integrating evidence in EU legislation [44]. This may entail the inclusion of economic arguments in BoD studies [76], as well as providing evidence directed to the EU context.

To fully embed BoD metrics in public health policy, a more systematic approach is needed. Several steps in that direction are required: the integration of DALYs into existing data generation systems, ensuring harmonisation of methodologies and data sources, timeliness, comprehensiveness and accessibility of databases [45,77]. As a political agreement has been reached for the European Health Data Space, reuse of health data (in a safe and harmonised environment) can represent a great opportunity for increasing the calculation of more accurate national and EU-level BoD estimates and for incorporating them into the EU policymaking process [78].

Knowledge translation remains an area underexplored by academia, which requires better impact analysis of scientific studies, especially in policymaking. The World Bank proposed a methodology that allows tracking the use of academic data, stating that scientific outputs contribute to increasing a country's economy and population [79]. Furthermore, Szomszor and Adie created a bibliometric database which allows tracking citations of scientific papers in policy document [80], assisting researchers quantify the impact of their outputs.

Limitations

Some limitations arise from the study. This analysis did not include quality-adjusted life years (QALY), a similar metric used in cost-effectiveness analyses, but not traditionally included as a BoD metric.

As EUR-Lex is dependent on the revision and publishing of the final legislation on the website, many documents already approved by EU entities might not have been available owing to the lag time between approval and publishing in EUR-Lex, thus not being accounted in this study. Furthermore, legislative files might take years to be developed, therefore institutional agendas and priorities may also influence the final approval of legislation.

Another limitation is the use of EUR-Lex as the sole data source. Many documents are published by the Joint Research Centre, which produces hundreds of documents yearly that support policymaking. However, the aim of our study was to interlink the BoD metrics with the EU legislation, which was only possible by analysing the published legislative files.

Finally, BoD metrics might have been used in public policies, but not explicitly stated in the policy documents, which presents as a limitation in the knowledge translation process. The inductive approach employed for the qualitative analysis has several limitations that are tied to researchers' bias and subjectivity (which could hamper replicability exercise) as well as lacking a theory as a starting point to frame the selected themes (which could lead to themes that could be deemed as too general); in addition, the inductive approach does not employ "a preexisting coding frame" [80].

Conclusion

Our study provided a first look into knowledge translation of BoD evidence to EU legislation, highlighting that its application remains primarily concentrated in environmental health domains. Health still is mainly seen as a national concern, as stated by the TFEU. Nevertheless, the EU has opportunities to expand its role in public health by advancing regulatory legislation on key health determinants such as transport, environmental exposures, and occupational risks.

Acknowledging the limitations in data scope and potential reporting biases, future research should focus on longitudinal studies to observe changes in the use of BoD metrics over time and consider qualitative interviews with policymakers to gauge the perceived value and barriers to their integration in legislative processes.

BoD evidence also calls for broader dissemination and targeted capacity-building efforts among researchers, public health

professionals, and policymakers. Subsequent studies should aim to establish a structured knowledge translation framework for BoD, offering practical guidance for policy integration and strategies to enhance communication and dissemination of findings.

Data availability statement

The data and the legislative files that support the findings of this study are available publicly at <https://eur-lex.europa.eu> and described in the Supplementary material files at [doi:10.1016/j.healthpol.2025.105387](https://doi.org/10.1016/j.healthpol.2025.105387).

Funding

This research was funded by Fundação para a Ciência e Tecnologia (FCT, Portugal) through national funds to the Associated Laboratory in Translation and Innovation Towards Global Health - REAL (LA/P/0117/2020).

CRediT authorship contribution statement

José Chen-Xu: Writing – original draft, Formal analysis, Validation, Conceptualization, Visualization, Data curation, Writing – review & editing, Methodology. **Diana Grad:** Writing – original draft, Investigation, Software, Data curation, Visualization, Formal analysis, Writing – review & editing, Methodology. **Nour Mahrouseh:** Visualization, Investigation, Writing – review & editing, Software, Data curation, Validation, Formal analysis, Writing – original draft, Methodology. **João Vasco Santos:** Methodology, Writing – review & editing, Conceptualization, Writing – original draft. **Silvia Riva:** Methodology, Writing – review & editing, Conceptualization, Writing – original draft. **Federica Gazzelloni:** Writing – original draft, Conceptualization, Writing – review & editing. **Brigid Unim:** Writing – original draft, Conceptualization, Validation, Writing – review & editing. **Periklis Charalampous:** Writing – review & editing, Conceptualization, Writing – original draft. **Enkeleint A. Mechili:** Writing – review & editing, Validation, Writing – original draft, Conceptualization. **Sarah Cuschieri:** Writing – review & editing, Validation, Writing – original draft, Conceptualization. **Vanessa Gorasso:** Writing – original draft, Writing – review & editing, Conceptualization. **Henk Hilderink:** Writing – review & editing, Methodology, Validation, Writing – original draft, Supervision. **Orsolya Varga:** Writing – original draft, Supervision, Validation, Writing – review & editing, Conceptualization. **Susana Viegas:** Supervision, Writing – original draft, Conceptualization, Writing – review & editing, Methodology, Validation.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

The authors would like to thank the European Burden of Disease Network for supporting the project, by providing a collaborative platform for capacity building and discussion.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.healthpol.2025.105387](https://doi.org/10.1016/j.healthpol.2025.105387).

References

- [1] Jenkins WI. Policy analysis: a political and organisational perspective. London: Robertson; 1978.
- [2] European Union. Consolidated version of the treaty on the functioning of the European Union. 2012. vol. 326.
- [3] McKee M, de Ruijter A. The path to a European Health Union. *Lancet Reg Health* 2024;36. <https://doi.org/10.1016/j.lanpe.2023.100794>.
- [4] World Health Organization. Evidence, policy, impact. WHO guide for evidence-informed decision-making. 2021.
- [5] Tomkins L, Bristow A. Evidence-based practice and the ethics of care: 'what works' or 'what matters'? *Hum. Relations* 2023;76:118–43. <https://doi.org/10.1177/00187267211044143>.
- [6] Murray CJL, editor. The global burden of disease: summary; a comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020. Geneva: World Health Organization; 1996.
- [7] World Health Organization. Global health estimates: life expectancy and leading causes of death and disability n.d. <https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates> [Accessed 11 February 2024].
- [8] Institute for Health Metrics and Evaluation. GBD results. Seattle, WA: IHME, University of Washington; 2020. <https://vizhub.healthdata.org/gbd-results/> [Accessed 11 March 2024].
- [9] Santos JV, Souza J, Valente J, Alonso V, Ramalho A, Viana J, et al. The state of health in the European Union (EU-28) in 2017: an analysis of the burden of diseases and injuries. *Eur J Public Health* 2020;30:590–5. <https://doi.org/10.1093/eurpub/ckz203>.
- [10] Cuschieri S, Calleja N, Devleesschauwer B, Wyper GMA. Estimating the direct Covid-19 disability-adjusted life years impact on the Malta population for the first full year. *BMC Public Health* 2021;21:1827. <https://doi.org/10.1186/s12889-021-11893-4>.
- [11] Porst M, Von Der Lippe E, Leddin J, Anton A, Wengler A, Breitkreuz J, et al. The burden of disease in Germany at the national and regional level—results in terms of disability-adjusted life years (DALY) from the BURDEN 2020 study. *Deutsches Ärzteblatt Int* 2022. <https://doi.org/10.3238/arztebl.m2022.0314>.
- [12] Devleesschauwer B, Willem L, Jurčević J, Smith P, Scohy A, Wyper GMA, et al. The direct disease burden of COVID-19 in Belgium in 2020 and 2021. *BMC Public Health* 2023;23:1707. <https://doi.org/10.1186/s12889-023-16572-0>.
- [13] Kim Y-E, Jung Y-S, Ock M, Yoon S-J. DALY estimation approaches: understanding and using the incidence-based approach and the prevalence-based approach. *J Prev Med Public Health* 2022;55:10–8. <https://doi.org/10.3961/jpmph.21.597>.
- [14] Mulholland E, Miller J, Bernard Y, Lee K, Rodríguez F. The role of NOx emission reductions in Euro 7/VII vehicle emission standards to reduce adverse health impacts in the EU27 through 2050. *Transport Eng* 2022;9:100133. <https://doi.org/10.1016/j.treng.2022.100133>.
- [15] Torres M, Nunes A, Martins JP, Ferreira PL, Pimenta R. Health care expenses impact on the disability-adjusted life years in non-communicable diseases in the European Union. *Front Public Health* 2024;12. <https://doi.org/10.3389/fpubh.2024.1384122>.
- [16] Gebeyehu DT, East L, Wark S, Islam MS. Disability-adjusted life years (DALYs) based COVID-19 health impact assessment: a systematic review. *BMC Public Health* 2023;23:334. <https://doi.org/10.1186/s12889-023-15239-0>.
- [17] Longfield K, Smith B, Gray R, Ngamkitpaiboon L, Violot N. Putting health metrics into practice: using the disability-adjusted life year for strategic decision making. *BMC Public Health* 2013;13:S2. <https://doi.org/10.1186/1471-2458-13-S2-S2>.
- [18] Pisoni E, Thunis P, De Meij A, Wilson J, Bessagnet B, Crippa M, et al. Modelling the air quality benefits of EU climate mitigation policies using two different PM2.5-related health impact methodologies. *Environ Int* 2023;172:107760. <https://doi.org/10.1016/j.envint.2023.107760>.
- [19] Veas C, Crispi F, Cuadrado C. Association between gender inequality and population-level health outcomes: panel data analysis of organization for Economic Co-operation and Development (OECD) countries. *EClinicalMedicine* 2021;39. <https://doi.org/10.1016/j.eclinm.2021.101051>.
- [20] Chen-Xu J, Varga O, Mahrouseh N, Eikemo TA, Grad DA, Wyper GMA, et al. Subnational inequalities in years of life lost and associations with socioeconomic factors in pre-pandemic Europe, 2009–19: an ecological study. *Lancet Public Health* 2024;9:e166–77. [https://doi.org/10.1016/S2468-2667\(24\)00004-5](https://doi.org/10.1016/S2468-2667(24)00004-5).
- [21] Deng P, Fu Y, Chen M, Wang D, Si L. Temporal trends in inequalities of the burden of cardiovascular disease across 186 countries and territories. *Int J Equity Health* 2023;22:164. <https://doi.org/10.1186/s12939-023-01988-2>.
- [22] European Commission. Directorate General for Research and Innovation. Futures of science for policy in Europe: scenarios and policy implications. LU: Publications Office; 2023.
- [23] European Commission. COM(2021) 44 final: communication from the commission to the European Parliament and Council. Europe's Beating Cancer Plan; 2021.
- [24] European Commission. In: COM/2020/381 final: communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions. A Farm to Fork Strategy for a fair, healthy and environmentally-friendly food system; 2020.
- [25] European Union. What is EUR-Lex? Publications Office; 2018. <https://doi.org/10.2830/383801>.
- [26] Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;n71. <https://doi.org/10.1136/bmj.n71>.
- [27] Timpel P, Harst L, Reifegerste D, Weihrach-Blüher S, Schwarz PEH. What should governments be doing to prevent diabetes throughout the life course? *Diabetologia* 2019;62:1842–53. <https://doi.org/10.1007/s00125-019-4941-y>.
- [28] European Union. EuroVoc Handbook. 2024.
- [29] Wildemuth B, editor. Applications of social research methods to questions in information and library science. 2nd ed. Santa Barbara, California: Libraries Unlimited, an imprint of ABC-CLIO, LLC; 2017.
- [30] McHugh ML. Interrater reliability: the kappa statistic. *Biochem Med* 2012;22: 276–82.
- [31] Koniaris M, Anagnostopoulos I, Vassiliou Y. Network analysis in the legal domain: a complex model for European Union legal sources. *J Complex Netw* 2018;6: 243–68. <https://doi.org/10.1093/comnet/cnx029>.
- [32] Bastian M, Heymann S, Jacomy M. Gephi: an open source software for exploring and manipulating networks. 2009.
- [33] Lumivero. NVivo (Version 14). 2023.
- [34] European Union. Proposal for a regulation of the European Parliament and of the Council establishing Horizon 2020 - The Framework Programme for Research and Innovation (2014-2020). 2011.
- [35] European Commission. COM/2009/0291 final: Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the regions on action against cancer : European Partnership. 2009.
- [36] European Commission. Commission staff Working Document - Country Report Italy 2020 accompanying the document communication from the Commission to the European Parliament, the European Council, the Council, the European Central Bank and the Eurogroup 2020. European Semester: assessment of progress on structural reforms, prevention and correction of macroeconomic imbalances, and results of in-depth reviews under Regulation (EU) No 1176/2011. 2020.
- [37] European Union. Regulation. (EU) No 282/2014 of the European Parliament and of the Council of 11 March 2014 on the establishment of a third Programme for the Union's action in the field of health (2014-2020) and repealing decision No 1350/2007/EC text with EEA relevance. 2014.
- [38] European Commission. Commission Staff Working Document - environmental implementation review 2022 country report - Romania Accompanying the document Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions Environmental Implementation Review 2022: turning the tide through environmental compliance. 2022.
- [39] European Commission. Commission Staff Working Document - impact assessment accompanying the document Proposal for a Directive of the European Parliament and of the Council amending Directive 2004/37 on the protection of workers from the risk related to exposure to carcinogens or mutagens at work. 2018.
- [40] Mathers CD. History of global burden of disease assessment at the World Health Organization. *Arch Public Health* 2020;78:77. <https://doi.org/10.1186/s13690-020-00458-3>.
- [41] Lopez AD. The evolution of the Global Burden of Disease framework for disease, injury and risk factor quantification: developing the evidence base for national, regional and global public health action. *Global Health* 2005;1:5. <https://doi.org/10.1186/1744-8603-1-5>.
- [42] Charalampous P, Gorasso V, Plass D, Pires SM, von der Lippe E, Mereke A, et al. Burden of non-communicable disease studies in Europe: a systematic review of data sources and methodological choices. *Eur J Public Health* 2022;32:289–96. <https://doi.org/10.1093/eurpub/ckab218>.
- [43] Cuschieri S, Alkerwi A, Economou M, Idavain J, Lai T, Lesnik T, et al. Conducting national burden of disease studies and knowledge translation in eight small European states: challenges and opportunities. *Health Res Policy Syst* 2022;20:113. <https://doi.org/10.1186/s12961-022-00923-1>.
- [44] Lundkvist A, El-Khatib Z, Kalra N, Pantoja T, Leach-Kemon K, Gapp C, et al. Policy-makers' views on translating burden of disease estimates in health policies: bridging the gap through data visualization. *Arch Public Health* 2021;79:17. <https://doi.org/10.1186/s13690-021-00537-z>.
- [45] Devleesschauwer B, Maertens de Noordhout C, Smit GSA, Duchateau L, Dorny P, Stein C, et al. Quantifying burden of disease to support public health policy in Belgium: opportunities and constraints. *BMC Public Health* 2014;14:1196. <https://doi.org/10.1186/1471-2458-14-1196>.
- [46] Public Health England. The burden of disease in England compared with 22 peer countries: a report for NHS England. 2020.
- [47] Public Health Scotland. Scottish Burden of Disease study Forecasting the future burden of disease: incorporating the impact of demographic transition over the next 20 years. 2022.
- [48] Sharma T, Funk T, Kuchenmüller T. The role of burden of disease analysis in evidence-informed policy-making. World Health Organization Regional Office for Europe; 2020.
- [49] Zheng P, Afshin A, Biryukov S, Bisignano C, Brauer M, Bryazka D, et al. The burden of proof studies: assessing the evidence of risk. *Nat Med* 2022;28:2038–44. <https://doi.org/10.1038/s41591-022-01973-2>.
- [50] Institute for Health Metrics and Evaluation. Burden of proof. Seattle, WA: IHME, University of Washington; 2022. <https://vizhub.healthdata.org/burden-of-proof/> [Accessed 14 March 2024].
- [51] Krishnan A. Understanding framing of public health issues and its relevance in climate change policy discourse. *Prevent Med* 2025;2:99–101. <https://doi.org/10.4103/pmrr.pmrr.257.24>.
- [52] Goniewicz K, Khorram-Manesh A, Burkle FM, Hertelendy AJ, Goniewicz M. The European Union's post-pandemic strategies for public health, economic recovery, and social resilience. *Glob Transit* 2023;5:201–9. <https://doi.org/10.1016/j.glt.2023.10.003>.
- [53] Vela Almeida D, Kolinjivadi V, Ferrando T, Roy B, Herrera H, Vecchione Gonçalves M, et al. The "greening" of Empire: the European Green Deal as the EU

- first agenda. *Polit Geogr* 2023;105:102925. <https://doi.org/10.1016/j.polgeo.2023.102925>.
- [54] Greer SL, Falkenbach M, Siciliani L, McKee M, Wismar M, Figueras J. From health in all policies to health for all policies. *Lancet Public Health* 2022;7:e718–20. [https://doi.org/10.1016/S2468-2667\(22\)00155-4](https://doi.org/10.1016/S2468-2667(22)00155-4).
- [55] Bronzwaer S, Catchpole M, de Coen W, Dingwall Z, Fabbri K, Foltz C, et al. One health collaboration with and among EU Agencies – bridging research and policy. *One Health* 2022;15:100464. <https://doi.org/10.1016/j.onehlt.2022.100464>.
- [56] European Commission. Health research and innovation. 2024. https://research-and-innovation.ec.europa.eu/research-area/health_en [Accessed 7 May 2024].
- [57] Arenliu Qosaj F, Bourdeaux M. Health policy developments in the Western Balkan countries 2000–19: towards European Health and Health Care policies. *Eur J Public Health* 2024. <https://doi.org/10.1093/eurpub/ckae045>. ckae045.
- [58] Mahrouseh N, Lovas S, Njuguna DW, Nellamkuzhi NJ, Soares Andrade CA, Sackey WE, et al. How the European Union legislations are tackling the burden of diabetes mellitus: a legal surveillance study. *Front Public Health* 2022;10. <https://doi.org/10.3389/fpubh.2022.1002265>.
- [59] Pallari E, Hilderink H. The concept of knowledge translation in relation to burden of disease. *Eur J Public Health* 2021;31. <https://doi.org/10.1093/eurpub/ckab164.509>. ckab164.509.
- [60] Prüss-Ustün A, Mathers C, Corvalán C, Woodward A. Assessing the environmental burden of disease at national and local levels: introduction and methods. Geneva: World Health Organization; 2003.
- [61] Knol AB, Petersen AC, van der Sluijs JP, Lebre E. Dealing with uncertainties in environmental burden of disease assessment. *Environ Health* 2009;8:21. <https://doi.org/10.1186/1476-069X-8-21>.
- [62] Seghier C, Ferré F, Tortù C, Bertarelli G, Mavrogianni C, Usheva N, et al. Addressing chronic diseases: a comparative study of policies towards type-2 diabetes and hypertension in selected European countries. *Eur J Public Health* 2024. <https://doi.org/10.1093/eurpub/ckae070>. ckae070.
- [63] Oliveira CB, Ferreira GE, Buchbinder R, Machado GC, Maher CG. Do national health priorities align with Global Burden of Disease estimates on disease burden? An analysis of national health plans and official governmental websites. *Public Health* 2023;222:66–74. <https://doi.org/10.1016/j.puhe.2023.06.038>.
- [64] Mitsakou C, Dimitroulopoulou S, Heavyside C, Katsouyanni K, Samoli E, Rodopoulou S, et al. Environmental public health risks in European metropolitan areas within the EURO-HEALTHY project. *Sci Total Environ* 2019;658:1630–9. <https://doi.org/10.1016/j.scitotenv.2018.12.130>.
- [65] European Environment Agency. EEA Report No 01/2024 - European climate risk assessment: executive summary. 2024.
- [66] World Health Organization. WHO/Europe and IHME sign agreement cementing collaboration on forecasting of health data. 2022. <https://www.who.int/europe/news/item/07-02-2022-who-europe-and-ihme-sign-agreement-cementing-collaborati-on-on-forecasting-of-health-data> [Accessed 11 March 2024].
- [67] World Health Organization. New memorandum of understanding between WHO and IHME brings better data and evidence for more informed decision-making for health. 2018. <https://www.who.int/europe/news/item/03-07-2018-new-memorandum-of-understanding-between-who-and-ihme-brings-better-data-and-evidence-for-more-informed-decision-making-for-health> [Accessed 11 March 2024].
- [68] Charalampous P, Haagsma JA, Jakobsen LS, Gorasso V, Nogueira I, Padron-Monedero A, et al. Burden of infectious disease studies in Europe and the United Kingdom: a review of methodological design choices. *Epidemiol Infect* 2023;151:e19. <https://doi.org/10.1017/S0950268823000031>.
- [69] von Cube M, Timsit J-F, Kammerlander A, Schumacher M. Quantifying and communicating the burden of COVID-19. *BMC Med Res Methodol* 2021;21:164. <https://doi.org/10.1186/s12874-021-01349-z>.
- [70] Nash K, Trott V, Allen W. The politics of data visualisation and policy making. *Convergence* 2022;28:3–12. <https://doi.org/10.1177/13548565221079156>.
- [71] Raineri P, Molinari F. Innovation in data visualisation for public policy making. In: Concilio G, Pucci P, Raes L, Mareels G, editors. The data shake: opportunities and obstacles for urban policy making. Cham: Springer International Publishing; 2021. p. 47–59. https://doi.org/10.1007/978-3-030-63693-7_4.
- [72] Eberhard K. The effects of visualization on judgment and decision-making: a systematic literature review. *Manag Rev Q* 2023;73:167–214. <https://doi.org/10.1007/s11301-021-00235-8>.
- [73] Zelizer A. How responsive are legislators to policy information? Evidence from a field experiment in a State legislature. *Legislative Stud Quart* 2018;43:595–618. <https://doi.org/10.1111/lsq.12206>.
- [74] Correa H, Namkoong K. Determinants and effects of health policy. *J Policy Model* 1992;14:41–63. [https://doi.org/10.1016/0161-8938\(92\)90023-6](https://doi.org/10.1016/0161-8938(92)90023-6).
- [75] Sinsowski J, Street JM. Evidence-informed public health policy. In: Quah SR, editor. International encyclopedia of public health (Second edition). Oxford: Academic Press; 2017. p. 57–65. <https://doi.org/10.1016/B978-0-12-803678-5.00150-8>.
- [76] Eijkemans GJM, Takala J. Moving knowledge of global burden into preventive action. *Am J Ind Med* 2005;48:395–9. <https://doi.org/10.1002/ajim.20227>.
- [77] European Centre for Disease Prevention and Control. Current and future burden of communicable diseases in the European Union and EEA/EFTA countries (BCoDE): methodology protocol. LU: Publications Office; 2011.
- [78] Li W, Quinn P. The European Health Data Space: an expanded right to data portability? *Comput Law Secur Rev* 2024;52:105913. <https://doi.org/10.1016/j.clsr.2023.105913>.
- [79] Stacy B, Kitzmüller L, Wang X, Mahler D, Serajuddin U. Missing evidence: tracking academic data use around the world (English). *Policy Res* 2024. working paper; no. WPS 10673; RRR; RSB; Washington, D.C.
- [80] Nowell LS, Norris JM, White DE, Moules NJ. Thematic analysis: striving to meet the trustworthiness criteria. *Int J Qual Methods* 2017;16:1609406917733847. <https://doi.org/10.1177/1609406917733847>.