Association of Schools of Public Health in the European Region (ASPHER), Public Health Emergencies Task Force

and the

European Burden of Disease Network (burden-eu)

April 2024

Learning about the European Burden of Disease from the COVID-19 Pandemic.

Joint Statement of shared understandings and on future directions for Burden of Disease strategies

On behalf of ASPHER and Burden-eu

ASPHER: John Reid, Neema Minja, Nadav Davidovitch

Burden-eu: Aline Anton (Robert Koch Institute), Alexander Rommel (Robert Koch Institute), Sara Pires (National Food Institute DTU), Brecht Devleesschauwer (Sciensano)

Introduction: These conclusions and recommendations are based on our recent Burden of Disease (BoD) report from the ASPHER COVID-19/Public Health Emergencies Task Force[1] and also the reports from the COVID-19 Task Force of Burden-EU.[2] The ASPHER COVID 19 Task Force (now the Public Health Emergencies Task Force) met throughout the pandemic to issue advice and support the European Schools of Public Health and other partners. Liaison and BoD updates were provided by Burden-EU over the last 12 months through linkages with RKI experts on BoD who led the project 'BoCO-19 – The Burden of COVID-19' during the pandemic, as part of the German government's Global Health Protection Programme (GHPP). Burden-EU and BoCO-19 provided substantial support to advance COVID-19 BoD work in most countries in Europe.[3]

We developed some general strategic joint recommendations and several more specific ones that are aligned below with the 4 key Lesson Areas from the ECDC (2023) report - Lessons from the Pandemic.[4]

Lesson Area 1: Investment in the public health workforce

Lesson Area 2: Preparing for the next public health crisis

Lesson Area 3: Risk communication and community engagement

Lesson Area 4: Collection and analysis of data and evidence.

General strategic recommendations

1. The COVID-19 pandemic has been a major challenge to each European country to estimate fully the burden of disease due directly to COVID-19 illness, to highlight health inequalities, and also the pandemic's indirect health impacts. We distinguish between the direct COVID-19-related disease burden (incl. post-COVID conditions) and the other health burdens during the pandemic from its wider impacts, including from pandemic countermeasures, such as on education, healthcare systems and economies.

Such direct and indirect health impacts should include injuries, illness, and disability, including mental health losses and impaired quality of life that have arisen from the pandemic. Much progress has been made, particularly on estimating the burden from the direct impacts of the COVID-19 infectious disease, but work on the wider pandemic health impacts and their uneven distribution remains to be completed. This programme would require a further phase of funding and identifying leadership and capacity.

We recommend a comprehensive work programme to assess fully the overall direct and indirect population health impacts, that will require continued post-pandemic BoD work across Europe during 2023-2025, to capture varied data sources and produce more comprehensive estimates of mortality, morbidity and disability.

2. Burden of Disease estimates initially focussed on important mortality measures, such as excess mortality, life expectancy, and Years of Life Lost. In addition, it is vital

to estimate the numbers of Years of Life Lived with Disability (YLD, also known as Years Lost due to Disability) following COVID-19 infection. The still-evolving understanding of the nature and levels of disability from COVID-19 infection from post-COVID conditions remains a major challenge. Disability Adjusted Life Years (DALYs) remain the core BoD metric for international comparisons. DALY findings are likely to be underestimated given YLD initially largely relied on pre-pandemic assumptions that could not have taken into account the still growing knowledge about post-COVID Conditions (PCC or "long-COVID").

We recommend developing and measuring severity distributions and disability weights for longer-term post COVID illness/disability based on validated and internationally comparable concepts, considering emerging research evidence.

We recommend that there should be comparable country-level population surveys and cohort studies of disability incidence and prevalence, enhancing recognised survey tools such as the EuroQoL (European Quality of Life descriptive system instrument) and addressing gaps in coverage in WHO European Region countries.

3. The pandemic's Burden of Disease has been widely reported to have exacerbated existing health inequalities, particularly worse affecting those people who have previous morbidities and disabilities, and population groups such as those experiencing deprivation and/or social exclusion, such as ethnic minorities and migrants. There is a need for greater clarity on what has been assessed so far, or is in progress, and what remains untackled.

We recommend that each European country compiles a wide-ranging pandemic profile that captures the inequalities of disease burdens of vulnerable population subgroups.

We recommend that expertise to independently advise on inequalities is drawn widely from European Schools of Public Health, from other academic disciplines and from applied experts in health informatics and health statistics.

Lesson Area 1: Investment in the public health workforce

4. The modern multidisciplinary public health workforce is diverse and includes personnel with different academic qualifications and work backgrounds. This may entail differential exposure to BoD concepts but also may provide different useful insights into BoD concepts and measurement approaches. Academic institutes, including schools of public health across Europe, vary in how much and what technical BoD content they teach on their masters and other courses. In-service training is also variable depending on the country and type of public health practitioner/specialist role occupied. The educational and training resources and activities developed by *Burden-EU* offer opportunities to build upon. This should cover standardisations in the definition of diseases, such as definitions of infected cases or deaths with or due to COVID-19), through harmonizing the coding practice across countries, which also involves better training of the health care professionals. There is a need to improve quality of data systems, such as death registrations, which are central to health

monitoring systems. This will need clearer definitions and overall improvements in health information systems that support BoD analyses.
We recommend that underlying theoretical principles and models, including surveillance pyramid paradigms, that recognise and correct for underdiagnosis and underreporting of infectious disease cases, should be explicitly recognised and taught in public health courses and in CPD.

We recommend that recent competency frameworks could be supplemented by additional thematic guidance on BoD content and quality of routine data as a foundation for estimating BoD.

We recommend that specialists who have advanced expertise in BoD measurement should be encouraged to offer affordable online resources for education, training and wider knowledge translation, including those from Burden-EU and Schools of Public Health or other Public Health Institutes/agencies.

Sufficient capacities in public health workforce should be made available as well as training opportunities for stakeholders in public health methodologies.

Lesson Area 2: Preparing for the next public health crisis

5. We recognise that 'updated, generic/all-hazard, flexible, scalable preparedness plans are needed' (ECDC 2023). Some countries will struggle more than others, given differences in their health needs and resources. Collaborative frameworks and support capacity are needed across all of Europe including middle- and low-income countries.

We support the sharing of preparedness plans across countries and that their BoD capabilities should be clearly set out in those plans.

We recommend that such broad generic plans also address prompt compilation of future probable excess and exacerbated burdens on those with pre-existing vulnerabilities and health inequalities, and that such plans show specific mitigation approaches that can be evaluated against eventual BoD outcomes for such population subgroups.

We recommend establishing national public health emergency operating centres, rapid health needs assessments, and support the use of BoD metrics as a supplement to early awareness systems.

We recommend that country level reporting templates be developed and that final country reports are produced by the end of 2025 that can offer the best credible overview of their BoD.

We recommend building and maintaining international public health networks, with rapid BoD reporting as a core function.

We recommend there should be improvement of each country's surveillance systems. This would include the integration of summary measures of population health, establishing of common dashboards and visualisation tools which can provide immediate attention to urgent problems.

Lesson Area 3: Risk communication and community engagement

6. Burden of disease reports were widely produced during the pandemic. Some attempted global comparisons that were generally useful for broad understanding, but were open to criticism at country level due to their assumptions and data variations across countries. Communication of BoD measures via media and journalists was commonplace and open to varied interpretation, indicating that there needs to be underlying mechanisms for linking to media outlets and pursuing objective briefing of journalists and policy makers. Scientific producers of reports also wished to highlight the early disparities and health inequalities that may have been overlooked or underreported. Gaining the trust of worst affected community groups in conducting credible reviews of burden of diseases is still an issue in some countries.

We recommend that the challenging experience of rapidly assessing BoD within a pandemic is harnessed by BoD experts and public health bodies in each country, via a national BoD Forum.

This BoD Forum could help prepare for better communication in future pandemics or disasters, for instance by reporting in different local languages, providing expert briefings and use of understandable infographics and visualisation tools for local populations, including those suitable for presentation to policy makers. We recommend that policymakers should be taught skills for risk communication and crisis management communication, that include explaining complex findings such as on BoD.

These should cover also indirect pandemic health impacts, including on children, on people with pre-existing chronic diseases/multi-morbidity, and on those suffering mental health impacts.

Each country BoD Forum should develop a stakeholder process to consult and feedback on its development. We should learn from and collaborate with public health practitioners, from neighbourhood to international levels, to support teaching, research and responses in the field of BoD. We should learn formally from examples of countries and regions that have widened public engagement in research priority setting, design and participation.[5,6]

Burden of Disease reports can be misunderstood, so we recommend integration in Public Health Institutes (PHIs) and academia and collaboration in Continuing Professional Education (CPE/CPD) actions with primary care practitioners and community workers. Also, to improve health information management by selecting adequate communication channels and maintaining Social Media presence. Further, we recommend fostering intersectoral collaboration for BoD information dissemination with many stakeholders in Knowledge Transfer and Exchange (KTE),[6] *such as journalists and other communications specialists, scientists, health professionals, NGOs and decision makers. Improved resources in professional communication and infodemic management integrated in PHIs and academia are useful to support the public with evidence-based information.*

Lesson Area 4: Collection and analysis of data and evidence.

7. European countries have had varied capacities to harness BoD data and to produce timely estimates of their pandemic health losses, whether YLL or YLD. Data should be capable of being disaggregated for different age, sex and vulnerability groups. There was a need for greater standardisation and harmonisation of methodologies and reporting efforts. Support has been given by Burden-EU to several countries to enhance their data capture and develop their expertise.

We recommend that each European country develops their international collaboration to strengthen harmonisation of BoD data sources, analysis and reporting, across the continent for future threats and pandemics.

We recommend an auditable international framework be developed across Europe that can allow each country to show their status and progression at regular intervals.

We recommend that disease and disability surveillance systems be updated, to include best practices in population health metrics (incl. BoD indicators) with cross-checking mechanisms on data quality and validity, diagnostics and genomics, with information provided via more integrated health information systems.

We recommend that our ability to respond and report BoD quickly should incorporate advanced and secure electronic data transfer systems, and online reporting platforms. In addition, integration is needed with other summary indicators of populations health, that measure hospitalization, disease symptoms and severity, and deaths with or due to the disease.

We recommend quantifying the benefit of preventive interventions actions and evaluation of mitigation measures, using BoD metrics.

We recommend exploring the practical implications to having ICD code transfer to registers/surveillance systems and establishing secure data access for researchers, through, for example, expansion of provision of Trusted Research Environments. Expanding data linkages should be more comprehensive, including mandatory reporting from private health care facilities to public health institutes in all countries that could enhance data quality. Regulatory changes may be needed to ensure the legal basis.

References:

1. Reid J, Minja N, Mabhala A, et al. How can Burden of Disease (BoD) measures that were used in the pandemic help in Examining European Health Inequalities (BoD-EEHI)? *ASPHER 2023.* https://www.aspher.org/download/1478/bod-aspher-paper-2023.pdf
2. European Burden of Disease Network. COVID-19. *burden-eu*. https://www.burden-eu.net/outputs/covid-19#top
3. Cawley C, Gabrani J, Stevanović A, Aidaraliev R, Çakmak Barsbay M, Cilovic Lagarija S, et al. The Burden of Disease due to COVID-19 (BoCO-19): A

study protocol for a secondary analysis of surveillance data in Southern and Eastern Europe, and Central Asia. *PLoS ONE* 2023;18(10): e0292041. https://doi.org/10.1371/journal.pone.0292041

4. European Centre for Disease Prevention and Control. Lessons from the COVID-19 pandemic. Stockholm: *ECDC*; 2023. https://www.ecdc.europa.eu/sites/default/files/documents/COVID-19-lessons-learned-may-2023.pdf
5. Gruer L, Ward H, Sheikh A, Kirkpatrick T, Bhopal R, Scottish Health and Ethnicity Linkage Study: Disseminating findings to the public and professionals: Raj Bhopal, *European Journal of Public Health*, Volume 27, Issue suppl_3, November 2017, ckx186.223, https://doi.org/10.1093/eurpub/ckx186.223
6. Pollok M, Gray E, Sakali J. Public perspectives on the use of health data in research and innovation. *IPSOS*, 2022. https://dataloch.org/sites/default/files/2022-06/Public%20perspectives%20on%20the%20use%20of%20health%20data%20in%20research%20and%20innovation.pdf
7. Macqueen Smith F. Knowledge Transfer and Exchange. In: Michalos AC. (eds) Encyclopedia of Quality of Life and Well-Being Research. 2014; 3477–3481. *Springer*, Dordrecht. https://doi.org/10.1007/978-94-007-0753-5_1580