

EUPHA's response to the European Commission's consultation on the European Health Data Space act 27 July 2022

The creation of a European Health Data Space (EHDS) is one of the key components of a strong European Health Union. The EHDS aims to facilitate the secondary use of data by promoting better access and exchange of different types of health data for research and policy purposes. This is essential for achieving EUPHA's vision: to enable everyone in Europe to achieve the highest possible level of health by providing independent and authoritative analysis of the evidence, combined with targeted advocacy to achieve coordinated action by all key stakeholders.

EUPHA therefore supports this important development for health in the EU, as shows from our participation in the EHDS pilot project, which will set up concrete foundations for the future EHDS by establishing an infrastructure for sharing and analyzing data between countries and testing this infrastructure by means of several use cases. Some of our member institutions and members of our section on Public Health Monitoring and Reporting also participate in the pilot project, illustrating the relevance of the topic for EUPHA and the knowledge on the secondary use of health data that is represented in our organization.

Thus, we feel that an EHDS can contribute significantly to better and more efficient public health research in Europe. It is good to see that the proposed regulation covers not only administrative registers (Electronic Health Records) but also research cohorts, survey data etc., which are (also) essential for population health monitoring and research (Article 33).

Establishing a health data access body (Article 37) for each country would make access of health data for secondary use much easier. However, there is a concern shall this also increase waiting time for approvals and data access as well as related costs.

Having national data catalogues (metadata descriptions of available data sources) will facilitate findability of potential data sources for research. However, this would require making the catalogues available not only in national language(s) but in English as well. In addition, to ensure usability, detailed information not only on data sources in general but also on the included variables would need to be made available. The latter would allow assessment of comparability, which is crucial for interpreting the outcomes of analyses based on internationally compiled data. In addition, systems between countries should be interoperable and have a common access point (Article 37q and Article 58).

We welcome the use of secure processing platforms (cloud computing platforms) that would allow secure data access and processing for cross-country collaborations. But again, we have some concerns about related costs for this (Article 370 and Article 52).

Finally, establishing interoperable systems between Member States would require capacity building activities and a help-desk function, as well as transparency regarding processes and sharing best practices (Article 59). Health information systems and levels of knowledge and capacities for developing and maintaining e.g., data catalogues and processing platforms vary widely between Member States at the moment.

In conclusion, EUPHA welcomes the establishment of the EHDS, and feels that the regulation proposal provides a solid basis for further discussion and development. In that further development, we urge to Commission to take into consideration various issues that, when not considered well and mitigated, could hamper the practical implementation and effectiveness of the EHDS. Most notably these relate to making sure that the EHDS will facilitate timely access of data for research at a reasonable cost and that data catalogues are genuinely usable across country borders, and taking into consideration the differences in terms of health information infrastructure, capacities and resources between Member States.



For more information, please contact office@eupha.org.

The European Public Health Association, or EUPHA in short, is an umbrella organisation for public health associations in Europe. Our network of national associations of public health represents around 25'000 public health professionals. Our mission is to facilitate and activate a strong voice of the public health network by enhancing visibility of the evidence and by strengthening the capacity of public health professionals. EUPHA contributes to the preservation and improvement of public health in the European region through capacity and knowledge building. We are committed to creating a more inclusive Europe, narrowing all health inequalities among Europeans, by facilitating, activating, and disseminating strong evidence-based voices from the public health community and by strengthening the capacity of public health professionals to achieve evidence-based change.

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