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European academy networks call for urgent solution to health data transfer barriers

April 8th, Brussels – Legal challenges hamper the sharing of health data with researchers outside the EU/European Economic Area (EEA), a new report by European academy networks concludes. The authors call for solutions to overcome these barriers to ensure timely and straightforward research collaboration in the public sector and thereby maximize health benefits for European citizens.

In the report “**International sharing of personal health data for research**” published today, the European Federation of Academies of Sciences and Humanities (ALLEA), the European Academies’ Science Advisory Council (EASAC), and the Federation of European Academies of Medicine (FEAM) call on EU policymakers and legislators for a commitment to overcome the barriers in sharing pseudonymised health data with researchers outside the EU/EEA, including the ones from the public sector, preferably under Article 46 of the General Data Protection Regulation (GDPR).

“EU/EEA citizens strongly benefit from international sharing of health data by allowing researchers to make best use of limited resources and to ensure that research conducted elsewhere is also relevant for patients in Europe. This must be encouraged and facilitated to maximise the individual and societal benefits to be obtained from the contribution of research participants”, emphasizes George Griffin, co-author of the report.

The GDPR was implemented before options for transferring data to countries outside of EU were operational. In particular, statutory conflicts between other countries’ legislation and EU fundamental rights have been a main challenge. This affects the direct transfer of public sector health data to foreign institutions and the possibility for external researchers to remotely access data at its original location. When institutions in other countries have statutory conflicts that prevent them from signing the required contracts under the GDPR, there is currently no workable legal mechanism for sharing health data for public sector research. It has been estimated that in 2019 more than 5,000 collaborative projects were affected between EEA countries and the US National Institutes of Health alone.

The authors stress that a solution is urgently needed, both for ongoing research collaborations as well as for new studies. “Collecting and combining health data is fundamental for the advancement of medical research and improving disease diagnosis and treatment. For research to thrive, pseudonymised personal data often needs to be shared internationally between research groups in a straightforward and timely fashion, whilst securing the protection of personal data”, says Volker ter Meulen, co-author of the report.

In the joint report, the three European academy networks focus on how global sharing of health data benefits public research, describe the challenges imposed by data protection regulations, and provide possible solutions through adapting or expanding the existing legal framework.

About the report

The joint report is based on discussions between experts from across Europe that were nominated by member academies of ALLEA, EASAC, and FEAM and acted in an individual capacity, bringing together all relevant disciplines and expertise for this topic of great shared importance for all. The participants convened virtually in two working group meetings (June 2020 and September

2020) and an online cross-sectoral roundtable (October 2020). The resulting draft report was peer-reviewed by independent academy-nominated experts.

Key takeaways from the report

- Health research is crucial for all: it benefits individual patients, population health, development of health-care systems, and social cohesion and stability.
- Sharing pseudonymised personal health data for public sector research is essential to make effective use of limited resources.
- Data must be shared safely and efficiently, taking account of privacy concerns: this is part of the conduct of responsible science and addressing these opportunities should be part of wider initiatives to build trust in research and researchers and to take account of patient views.
- Legal challenges have resulted in impediments to data sharing with researchers outside the EU/EEA, affecting both the direct transfer of data to non-EU/EEA countries and remote access to data at its original location.
- There must be increased commitment by the European Commission to urgently overcome these barriers in sharing data. Preferably, a simple and consistent operational solution would be found under Article 46 of the GDPR, whilst protecting the privacy of personal data from EU/EEA citizens.

About ALLEA

ALLEA is the European Federation of Academies of Sciences and Humanities, representing more than 50 academies from over 40 EU and non-EU countries. Since its foundation in 1994, ALLEA speaks out on behalf of its members on the European and international stages, promotes science as a global public good, and facilitates scientific collaboration across borders and disciplines. Jointly with its members, ALLEA seeks to improve the conditions for research, to provide the best independent and interdisciplinary science advice available, and to strengthen the role of science in society. [Read more](#). Contact: secretariat@allea.org

About EASAC

EASAC is formed by the national science academies of the EU Member States, Norway, Switzerland and UK, to collaborate in giving advice to European policy-makers. EASAC provides a means for the collective voice of European science to be heard. Through EASAC, the academies work together to provide independent, expert, evidence-based advice about the scientific aspects of European policies to those who make or influence policy within the European institutions. Drawing on the memberships and networks of the academies, EASAC accesses the best of European science in carrying out its work. Its views are vigorously independent of commercial or political bias, and it is open and transparent in its processes. EASAC aims to deliver advice that is comprehensible, relevant and timely. [Read more](#). Contact: secretariat@easac.eu

About FEAM

FEAM is the European Federation of National Academies of Medicine and Medical Sections of Academies of Sciences. It brings together under one umbrella 23 National Academies representing thousands among the best scientists in Europe. FEAM's mission is to promote cooperation between National Academies of Medicine and Medical Sections of Academies of Sciences in Europe; to provide a platform to formulate their collective voice on matters concerning human and animal medicine, biomedical research, education, and health with a European dimension; and to extend to the European authorities the advisory role that they exercise in their own countries on these matters. [Read more](#). Contact: info@feam.com

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The full report

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