

Introduction to ALLEA- EASAC-FEAM project on international data sharing for health research



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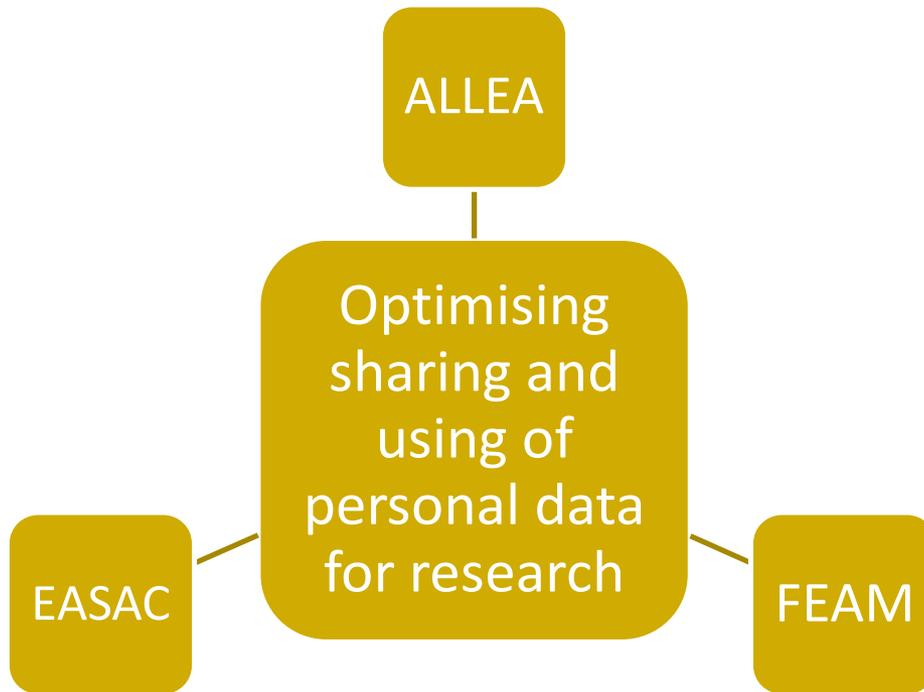
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EASAC

Mutual interests of European academy networks

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EU Institutions' interests in protecting and using data for research

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- *“Health and disease are global.....Any research and action plan must include a European- and world-wide dialogue”* EU Scientific Panel for Health 2016
- GDPR:
 - Protecting personal data in EU/EAA and international transfer
 - Commission, Parliament and Council of Ministers agreed compromise position enabling scientific research to continue under GDPR
 - But implementation associated with barriers to international sharing
- Other recent developments e.g. EU Data Strategy and Health Data Space: are these again too inward looking?

Value of public sector health research



- Benefits patients and society, reduces inequalities, supports development of health care systems
- Collaborative research and data sharing important to ensure sufficiently large sample sizes, especially for rare diseases and disease subsets, to identify complex pathways, improve diagnosis and treatment, make the most of limited resources and contribution by patients and volunteers to research
- International data sharing important to compare determinants and outcomes of disease in different settings, assess relevance to EU/EEA patients, develop new research areas and big data

Examples of European value of collaborative health research

- Understanding risk factors for blood pressure
- Understanding risk factors for suicide in schizophrenia
- Exploring linkage between diabetes treatment and cancer
- Establishing association between smoking and lung cancer
- Microbiomics and pharmaceutical research
- COVID-19
- See Report appendix 2 for other examples and further detail



What EU/EEA contributions to international research have been stalled?



- US National Cancer Institute Cohort Consortium (worldwide)
- WHO International Agency for Research on Cancer
- Psychiatric Genomics Consortium for rare subtypes in psychosis, bipolar and eating disorders
- International Genomics of Alzheimer's Consortium
- Disease prevention strategies: vaccination and child health programmes
- Infectious disease (only initial COVID-19 data transfers covered by derogation) and antimicrobial resistance
- See Report Box 4 and Appendix 2 for other examples and further detail

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ALLEA-EASAC-FEAM collaborative project

- Proposed by Norwegian colleagues to EASAC Biosciences Steering Panel meeting (with FEAM), October 2019. Proposal agreed by Councils of ALLEA, EASAC, FEAM November-December 2019
- Working Group participation: Austria, Belgium, Estonia, Germany, Italy, Netherlands, Norway, Poland, Portugal, Sweden, Switzerland, UK
- Expertise in medicine, ethics, informatics, social sciences
- Discussions with DG Justice and FEAM Forum (including patients, pharmaceutical industry and European Federation of Medical Informatics)
- Consensus report peer reviewed December 2020-February 2021

Objectives of the joint project



- Reaffirming value of health research to all, and importance of sharing data
- Raising visibility of GDPR obstacles for international sharing of personal health data for public sector research
- Clarifying principles for: seeking simple solution respectful of fundamental rights that does not conflict with other countries legislation
- Setting into context with other EU policy
- Taking account of other factors, e.g. Privacy-Enhancing Technologies
- Conclusions directed to EU Commission, Parliament and Council of Ministers, EU/EEA Member States, researchers, research institutions and funders, plus international audience

Report published 8 April 2021

See also Gould, Lancet Oncology online April 15 2021

Nature Medicine In Press

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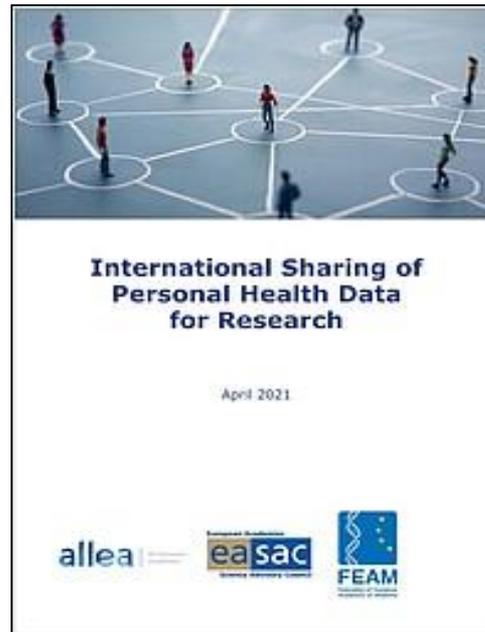
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In conclusion

- Timely and important project
- Main recommendations will be presented by Rosa Castro
- Sharing personal health data for research benefits all
- Patients are supportive:
 - FEAM Forum noted *“92% of European patients are willing to share health data and 60% support cross-border sharing”*.
 - But there is still controversy and concern and European scientific community must do more to engage in building public trust