The joint ALLEA-EASAC-FEAM report on international data sharing for health research

Rosa Castro
Senior Scientific Policy Officer
Federation of European Academies of Medicine (FEAM)
• European umbrella group of 23 national Academies including Medicine, Medical Sections of Academies of Sciences, Pharmacy and Veterinary Sciences

• Expertise of scientists from across the biomedical disciplines in Europe

• Independent scientific advice on human and animal medicine, biomedical research, education and health priorities

• Capacity to inform the EU biomedical policy process at European and national level, via its Academies
Cross sectoral cooperation
FEAM European Biomedical Policy Forum

• Platform launched in autumn 2017

• Bringing together European biomedical stakeholders (academia, research, civil society, industry, health-related organisations)

• Safe haven for policy discussion and exchange under FEAM umbrella

• Policy meetings with partners; facilitating engagement with European policy makers

International Transfer of Health Data
Cross-sectoral roundtable - Summary report
16 October 2020
<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tbody>
<tr>
<td>2012-2015</td>
<td>European Commission GDPR first proposed text</td>
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<td>2014-2015</td>
<td>Implementation of the GDPR</td>
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<td>2018</td>
<td>FEAM welcomes the proposals and asks for clarifications to address barriers to health research</td>
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<tr>
<td>2019</td>
<td>FEAM Forum: Academies’ early assessment of GDPR raises concerns about extra costs for research and delay or abandonment of projects</td>
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<td>2020</td>
<td>EDPB Guidelines</td>
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<td>2021</td>
<td>Schrems II judgement by the European Court of Justice invalidating the US Privacy Shield</td>
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<td>ALLEA report with the Royal Society “Flourishing in a data-enabled society”</td>
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<td>Start of the joint ALLEA-EASAC-FEAM project</td>
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<td>Publication of the joint ALLEA-EASAC-FEAM report on International Sharing of Personal Health Data for Research</td>
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Key messages of the joint report (1)

• Health research is crucial and its value should be better communicated

• Sharing pseudonymised personal health data with public sector researchers outside of the EU/EEA makes effective use of limited resources & maximises the value of contributions by patients & volunteers

• Addressing potential privacy concerns with data sharing is critical to take account of patient views & build trust in research and researchers
Key messages of the joint report (2)

• GDPR affects both the direct transfer of data and remote access to data at its original location, as well as secondary uses of data by institutions outside of the EU/EEA.

• Solutions call for better options within article 46 of the GDPR; guidance by the European Data Protection Board & examples with further guidance for health researchers.

• Other issues such as interoperability, and other methodological and technical quality issues need to be addressed to facilitate efficient and secure data sharing for research.

• Privacy enhancing technologies can improve data security but their use does not circumvent the data transfer requirements of the GDPR.
How is the report being used?
Communicating messages to EU policymakers

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**Health experts call for the GDPR revision for cross-border health data sharing**

By Giedre Peseckyte | EURACTIV.com

8 Apr 2021 | News

Data protection rules ‘harming EU leadership’ in health research, says report

Confusion over GDPR is blocking scientific progress, throwing up barriers with US researchers in particular. More than 5,000 projects were affected in 2019 and the problem is ‘escalating’

By Emma Kelly

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Between facilitating health research cooperation and protecting citizens’ privacy, Europe inadvertently picked the latter.

In the midst of the coronavirus pandemic — and three years after Europe’s flagship data protection law, the GDPR, went live — Euros rules so that they can transfer EU data outside the bloc for research.

Medical workers and public health authorities are already straining to understand COVID-19 and its developing variants, not to mention sharing that research is making a difficult job even more complex.

“We are stuck,” said Giske Ursin, director of the Cancer Registry of Norway, a research institute.

Transatlantic research has been at the center of concerns. Many European researchers work with American public institutions. The US research in the world, investing more than $40 billion every year, some of which is spent on collaborative research projects with Eurc
Discussions at national level also via Member Academies
A public discussion with EU policymakers and other stakeholders

• Focused on broad implications for the healthcare sector of an adequacy decision for the UK—including for health research

• 380 participants including key decision-makers in EU-UK data transfers approval process

• Webinar recording available here

• Participants received a copy of the joint report and invitation to the discussion event on 3 June
With the participation of the Presidents of ALLEA (Antonio Loprieno), EASAC (Christina Moberg), and FEAM (George Griffin) and Volker ter Meulen (co-chair of the joint working group)

Confirmed speakers

- Axel Voss, Member of the European Parliament
- Robert Eiss, US National Institutes of Health
- Gözde Susuzlu Briggs, Data Saves Lives, European Patients’ Forum
- Brendan Barnes, European Federation of Pharmaceutical Industries Associations
- Giske Ursin, Cancer Registry of Norway
- Heidi Beate Bentzen, University of Oslo
- Rosa Castro, FEAM
- Alisa Vekeman, European Commission, DG Justice (to be confirmed)