Gesundheit Österreich GmbH

Data and Public Health Research – A story of legal challenges

VIRTUAL WORKSHOPS ON COMMON GOVERNANCE PRINCIPLES FOR THE RE-USE OF HEALTH DATA – DAY 2.

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Research in Digital Times

- … is no longer restricted to traditional research organisations like universities or research labs → Facebook declares that their Human Computer Interaction (HCI) and User Experience (UX) researchers are e.g. learning how developing countries use mobile phones for maternal health https://research.fb.com/category/human-computer-interaction-and-ux/
- … could be defined very broadly → Frascati criteria of OECD e.g., consider "the involvement of staff with doctoral degrees" as indicator (http://oe.cd/frascati, p. 69)
- … has a habit of "early publishing" resp. publishing of pre-findings on digital platforms → leading to situations like e.g., the Mehra et al. 2020 "Hydroxychloroquine or chloroquine Case" with most likely a lot of at least wrongly collected registry data https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)31290-3/fulltext
- … Demands higher skills and capacity in reading and digesting new evidence and research findings → PubMed Search for CoV*, Corona*, SARS-CoV* and COVID-19* yielded 80.000 papers only in 2020 https://pubmed.ncbi.nlm.nih.gov/ besides ECDC, WHO, EPH, EC reports

Plethora of legal stipulations

EU LEVEL

- Art. 13 of Fundamental Rights "*The arts and scientific research shall be free of constraint. Academic freedom shall be respected.*"
- Art. 179 Treaty on the Functioning of the European Union stating *".. the objective of strengthening its scientific and technological bases by achieving a European research area in which researchers, scientific knowledge and technology circulate freely, and encouraging it to become more competitive, including in its industry, while promoting all the research activities deemed necessary by virtue of other Chapters of the Treaties."*
- GDPR, especially Art. 89 "*Safeguards and derogations relating to processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes*"
- 'Open Data Directive (EU) 2019/1024' requires Member States to "s*upport the availability of research data"* with measures to make "*publicly funded research data openly available"*

MS Level

- Health Professions Law
- Pharmaceutical and Medical Device Law
- National Research Laws, etc.

Leading into ….

- Different interpretation of GDPR by Member States (and between different Data Protection Officers)
- Role of further national stipulations (e.g. on regional level) and “execution of law”
- Debate around “anonymised” versus “pseudonymised” data
- Wide Interpretation of consent-based data sharing, especially cross-country
- Confusion regarding role of ethics committee in public health research (e.g., in UK mandatory – in AT there is not even an Data Ethics Board in place)
- Conflicting public interest, very well visible in times of crisis → e.g., contact tracing (whether via apps or by the police) and personal data protection

→ Summing up: Use of data for research is more complex than ever