

Publication

Research Ethics in the European Influenzanet Consortium: Scoping Review

JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

ID 4486819

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Year 2018

Title Research Ethics in the European Influenzanet Consortium: Scoping Review

Journal JMIR public health and surveillance

Volume 4

Number 4

Pages / Article-Number e67

Influenzanet was launched in several European countries to monitor influenza-like illness during flu seasons with the help of volunteering participants and Web-based technologies. As in the case of developing fields, ethical approaches are not well developed in the collection, processing, and analysis of participants' information. Existing controversies and varying national ethical regulations can, thus, hamper efficient cross-border research collaboration to the detriment of quality disease surveillance.; This scoping review characterizes current practices on how ethical, legal, and social issues (ELSI) pertinent to research ethics are handled by different Influenzanet country groups to analyze similarities and identify the need for further harmonization of ethical approaches.; A literature search was carried out on PubMed, Web of Science, Global Digital Library on Ethics, and Bioethics Literature Database to identify ELSIs for Influenzanet country platforms. Only English-language papers were included with publication dates from 2003 to 2017. Publications were screened for the application of bioethics principles in the implementation of country platforms. Additional publications gathered from the Influenzanet Consortium website, reference screening, and conference proceeding were screened for ELSIs.; We gathered 96 papers from our search methodology. In total, 28 papers that mentioned ELSIs were identified and included in this study. The Research Ethics Committee (REC) approvals were sought for recruiting participants and collecting their data in 8 of 11 country platforms and informed e-consent was sought from participants in 9 of 11 country platforms. Furthermore, personal data protection was ensured throughout the Consortium using data anonymization before processing and analysis and using aggregated data.; Epidemics forecasting activities, such as Influenzanet, are beneficial; however, its benefits could be further increased through the harmonization of data gathering and ethical requirements. This objective is achievable by the Consortium. More transparency should be promoted concerning REC-approved research for Influenzanet-like systems. The validity of informed e-consent could also be increased through the provision of a user friendly and standard information sheet across the Consortium where participants agree to its terms, conditions, and privacy policies before being able to fill in the questionnaire. This will help to build trust in the general public while preventing any decline in participation.

ISSN/ISBN 2369-2960

edoc-URL <https://edoc.unibas.ch/66286/>

Full Text on edoc No;

Digital Object Identifier DOI 10.2196/publichealth.9616

PubMed ID <http://www.ncbi.nlm.nih.gov/pubmed/30305258>

ISI-Number MEDLINE:30305258

Document type (ISI) Journal Article, Review