Universität Basel

Research Project

Role of plain language materials in democratizing access to medical research data for patients/caregivers and lay public

Project funded by own resources

Project title Role of plain language materials in democratizing access to medical research data for patients/caregivers and lay public
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Organisation / Research unit
Ethik / Bio- und Medizinethik (Elger)
Project start 01.09.2022
Probable end 31.07.2026
Status Active
Role of Plain Language Materials in Democratizing Access to Medical Research Data for Patients/Caregivers and Lay Public
Background: The primary purpose of clinical trials is to evaluate the risk:benefit profile of any investigational therapies/products/devices before making the most effective therapies/modalities available for wider use. Consequently, access to clinical trial data is restricted to regulators for drug review/approval process, to payers for reimbursement review process, and to physicians who are the prescribers. Nevertheless, there has been a growing demand for access to medical research data for a wider stakeholder group beyond the scientific community, such as patients/caregivers and lay public, who are the eventual end-users of these approved therapies. While the focus on making patient-level data accessible to the research community has gained momentum, the needs of the wider non-scientific stakeholder group remain largely unmet. This group can benefit significantly from plain language materials that are accessible, accurate, and easy to understand. This will not only allow patients/caregivers to participate in shared decision-making for their disease management, equip lay public to identify/question misinformation but also increase inclusiveness/equity in healthcare access.
Research questions: (1) What barriers exist in the current settings that impede access to latest medical research (clinical trial data) in plain language, among patients/caregivers and lay public? (2) What formats of plain language materials and dissemination channels can enable timely and wider dissemination of accurate and easy-to-understand medical research?

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