The Ethics of Data Access, Use, and Sharing for Human Subjects Research
March 1, 2017
Boston, Massachusetts

Bibliography

Part I: What is Possible? The value and limitations of access, use, and sharing of health, research, and patient-generated data for science and society


Part II: Conceptualizing an individual’s rights, interests, and expectations with regard to their health and other data.


Part III: Implications for consent, authorization, and data stewardship


Part IV: Implications for oversight of data sharing and use: Who is safeguarding subject rights?


Public and Private Data Access and Sharing Requirements


Article and Data Sharing Requirements by Federal Agency. SPARC. (2017).


