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	Descrizione fisica	1 online resource (xiv, 188 pages) : digital, PDF file(s)
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Nota di bibliografia	Includes bibliographical references and index.
Nota di contenuto	Introduction -- Data, biospecimens, and research -- Privacy, confidentiality, safeguards -- Broad privacy and the data protection regimes -- Healthcare, public health, and research regimes -- Consent -- Identifiability and person-specific data -- Genetics and genomics -- Safeguards and responsibilities -- Data sharing, access, and transfer -- Ways forward.
Sommario/riassunto	The potential of the e-health revolution, increased data sharing, database linking, biobanks and new techniques such as geolocation and genomics to advance human health is immense. For the full potential to be realized, though, privacy and confidentiality will have to be dealt with carefully. Problematically, many conventional approaches to such pivotal matters as consent, identifiability, and safeguarding and security are inadequate. In many places, research is impeded by an overgrown thicket of laws, regulations, guidance and governance. The challenges are being heightened by the increasing use of biospecimens, and by the globalization of research in a world that has not globalized privacy protection. Drawing on examples from many developed countries and legal jurisdictions, the book critiques the issues, summarizes various ethics, policy, and legal positions (and revisions underway), describes innovative solutions, provides extensive references and suggests ways forward.