1.	Record Nr.	UNINA9910452610303321
	Titolo	Governing biobanks : understanding the interplay between law and practice / / by Jane Kaye [and others]
	Pubbl/distr/stampa	Oxford [England];; Portland, Oregon:,: Hart Publishing,, 2012
	ISBN	1-4725-6584-3 1-281-06329-0 9786613773982 1-84731-883-5
	Edizione	[1st ed.]
	Descrizione fisica	1 online resource (380 p.)
	Disciplina	344.4204194
	Soggetti	Biobanks - Law and legislation - Great Britain Biobanks - Law and legislation Biobanks - Management Electronic books.
	Lingua di pubblicazione	Inglese
	Formato	Materiale a stampa
	Livello bibliografico	Monografia
	Note generali	Description based upon print version of record.
	Nota di bibliografia	Includes bibliographical references and index.
	Nota di contenuto	From an idea to a project / Jane Kaye [et al.] Embedding biobanks in a changing context / Jane Kaye Mapping the regulatory space / Susan M.C. Gibbons Dynamic networks of practice / Catherine Heeney Governance in practice : patterns of awareness and engagement / Susan M.C. Gibbons and Andrew Smart General attitudes to governance / Susan M.C. Gibbons and Andrew Smart Attitudes to particular laws and governing bodies / Susan M.C. Gibbons and Andrew Smart Preferences for governance / Susan M.C. Gibbons and Andrew Smart Enacting governance : the case of access / Catherine Heeney and Andrew Smart Reflections on practice and governance / Jane Kaye Ethics and the governance of biobanks / Catherine Heeney and Michael Parker.
	Sommario/riassunto	"Biobanks are proliferating rapidly worldwide because they are powerful tools and organisational structures for undertaking medical research. By linking samples to data on the health of individuals, it is anticipated that biobanks will be used to explore the relationship between genes, environment and lifestyle for many diseases, as well as the potential of

individually-tailored drug treatments based on genetic predisposition. However, they also raise considerable challenges for existing legal frameworks and research governance structures. This book critically examines the current governance structures in place for biobanks in England and Wales. It shows that the technologies, techniques and practices involved in biobanking do not always conform neatly to existing legal principles and frameworks that apply to other areas of medical research. Using a socio-legal approach, including interview data gathered from the scientific community, this book provides unique insights and makes recommendations about appropriate governance mechanisms for biobanking in the future. It also explores the issues around the secondary use of information, such as consent and how to protect privacy, when biobanks are accessed by a number of different third parties. These issues have relevance both within England and Wales and to a wide international audience, as well as for other areas where large datasets are used."--Bloomsbury Publishing.