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Nota di contenuto	The medium and the message : tissue samples, genetic information, and data protection legislation / Neil C. Manson -- Me, myself, I : against narcissism in the governance of genetic information / Søren Holm -- Decisions, consent and expectations of the individual / Caroline Mullen -- Constructing communal models of governance : collectives of individuals or distinct ethical loci? / Heather Widdows -- Rights, responsibility and stewardship : beyond consent / Roger Brownsword -- Who decides what? : relational ethics, genetics and well-being / Sarah Wilson -- Involving publics in biobank governance :

moving beyond existing approaches / Kathryn G. Hunter and Graeme T. Laurie -- Genetic information and public opinion / Andrew Edgar -- Harmonisation and standardisation in ethics and governance : conceptual and practical challenges / Ruth Chadwick and Heather Strange.

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Sommario/riassunto

This volume maps the areas of ethical concern in the debate regarding the governance of genetic information, and suggests alternative ethical frameworks and models of regulation in order to inform its restructuring. Genetic governance is at the heart of medical and scientific developments, and is connected to global exploitation, issues of commodification, commercialisation and ownership, the concepts of property and intellectual property and concerns about individual and communal identity. Thus the decisions that are made in the next few years about appropriate models of genetic governance will have knock-on effects for other areas of governance. In short the final answer to 'Who Decides?' in the context of genetic governance will fundamentally shape the ethical constructs of individuals and their networks and relationships in the public sphere.

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