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Nota di contenuto	Front Matter -- Contents -- List of figures and photographs -- List of abbreviations -- Authors and contributors, with current positions -- Acknowledgements -- Foreword -- Preface -- Introduction -- ALSPAC Ethics and Law Committee: a new concept -- Preliminaries and pioneers: framing the questions -- Informal or casual: an unusual style -- Advisory to independent: a missed opportunity -- Bureaucratic battles: liaison with Local Research Ethics Committees -- Policy development: a case of case law -- Confidentiality and anonymity: a rod for their own backs -- Informed consent: too much information -- Child protection: an observational study? -- Disclosure of individual results: foreseen feedback and incidental findings -- Disclosure of individual results: participants' requests -- Participants' problems: people not policies -- External databases: anonymous linkage -- Beyond policy: a broad remit -- Retention of the Cohort: incentives or inducements -- Commercial collaborations: selling our souls -- Comprehensive oversight: undocumented and unacknowledged -- Influence beyond ALSPAC: extension of expertise -- Conclusions -- Postscript -- Notes -- References -- ALSPAC Steering Committee: founding members -- ALSPAC Ethics and Law Committee members: appointed 1990-2005 -- Letter to participants: further information concerning confidentiality -- Young Mothers paper by Elizabeth Mumford -- The Children of the Nineties study (ALSPAC) and collaboration with pharmaceutical companies -- Index

"Available Open Access under CC-BY-NC licence The Avon Longitudinal Study of Parents and Children (ALSPAC), also known as Children of the 90s, is a world-leading birth cohort study that uniquely enrolled participants in utero and obtained genetic material from a geographic population. It instigated the innovative but controversial ALSPAC Ethics and Law Committee.

This book describes in detail the early work of this Committee, from establishing the core ethical principles necessary to protect participants, to the evolution of policies concerning confidentiality and anonymity, consent, non-intervention and disclosure of individual results, data access and security. Quotes from interviews with early members of the Committee reflect not only on its pioneering work but also on the unusual style and inspirational leadership of the first Chair, Professor Michael Furmston.

This will be of interest to those involved in other cohort studies in understanding the evolution of ethical policies as ALSPAC developed."

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