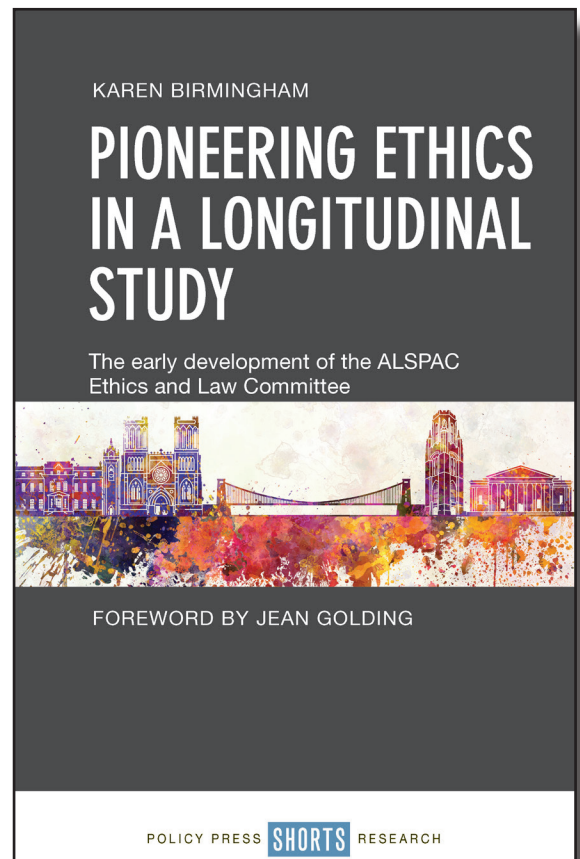


Pioneering ethics in a longitudinal study

The early development
of the ALSPAC Ethics and
Law Committee

Karen Birmingham, University of Bristol

FOREWORD BY JEAN GOLDING



"A fascinating account of a pioneering study, which developed ethical procedures in an evolving context with no existing coherent framework." Anna Tarrant, University of Lincoln

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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 & 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.

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