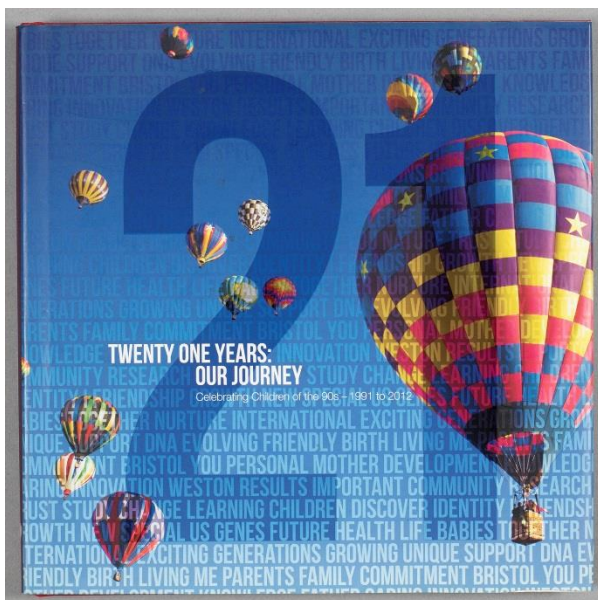


HARG Workshop

London School of Hygiene & Tropical Medicine, 17 July 2017

ALSPAC ADMINISTRATIVE ARCHIVE PROJECT



Hannah Lowery,

Special Collections Archivist and Manager

Mike Hunkin,

Project Archivist 1, Sept 2015-February 2017

Karen Anderson,

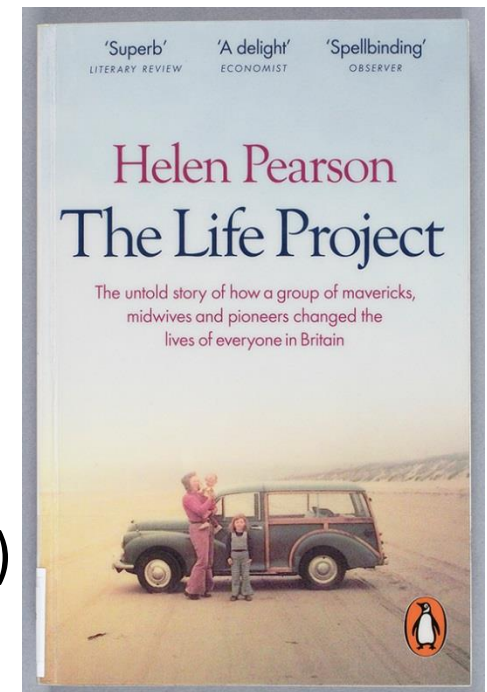
Project Archivist 2, May 2017 to date



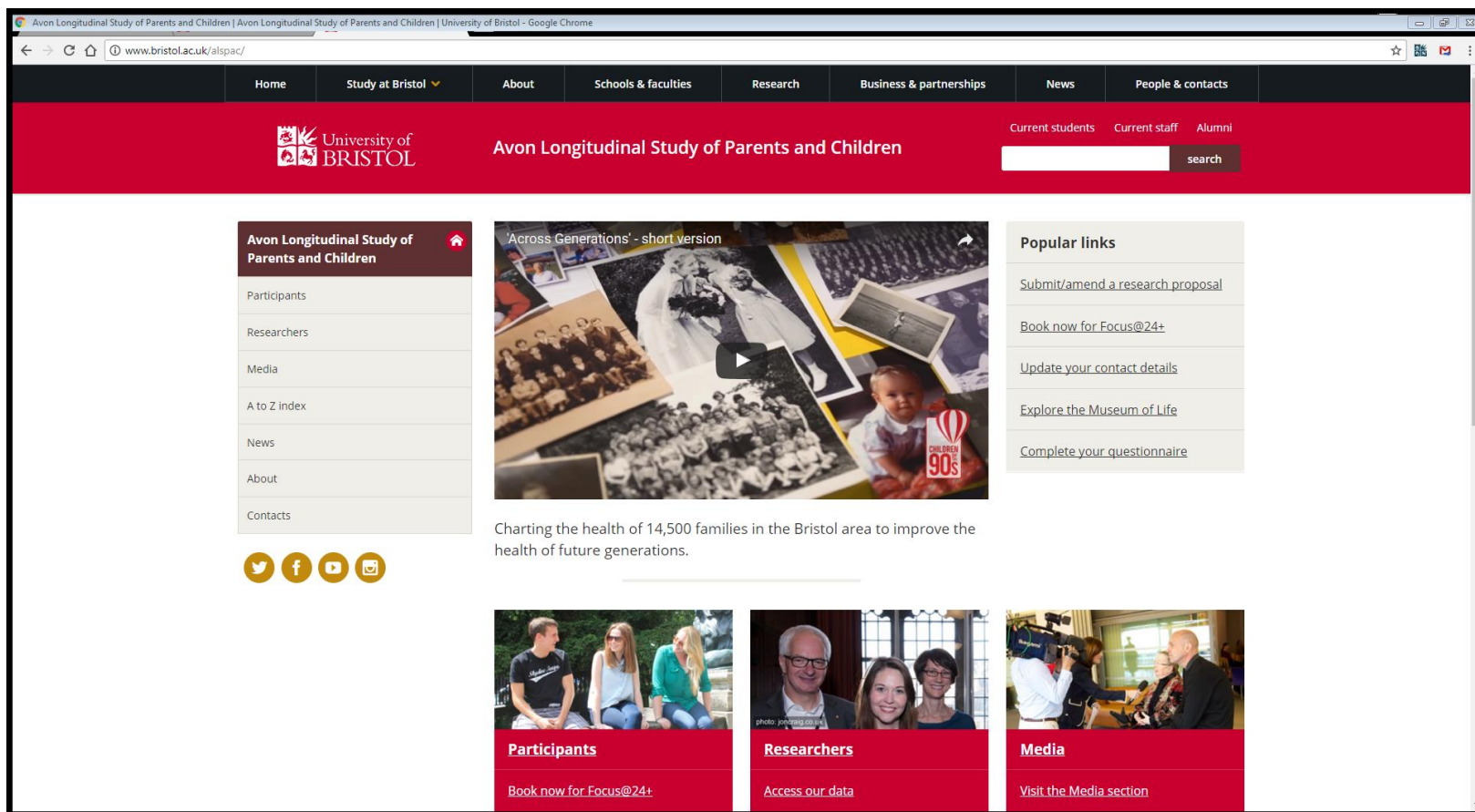
ALSPAC ADMINISTRATIVE ARCHIVE PROJECT

What is ALSPAC?

- Avon Longitudinal Study of Parents and Children aka “Children of the Nineties”
- Longitudinal study of children born in the Bristol/Avon Area, 1991/1992
- Project covers 1980s to c.2005
(and there will be more to come as the project continues)
- Helen Pearson, *The Life Project*, (Penguin, 2016)
- ALSPAC website



ALSPAC ADMINISTRATIVE ARCHIVE PROJECT



The screenshot shows the ALSPAC website interface. At the top is a navigation bar with links: Home, Study at Bristol, About, Schools & faculties, Research, Business & partnerships, News, and People & contacts. Below this is a red header banner with the University of Bristol logo, the text 'Avon Longitudinal Study of Parents and Children', and links for 'Current students', 'Current staff', and 'Alumni'. A search bar is also present. On the left is a sidebar menu with links: Participants, Researchers, Media, A to Z index, News, About, and Contacts. Below the menu are social media icons for Twitter, Facebook, YouTube, and Instagram. The main content area features a video player titled 'Across Generations' - short version, showing a collage of historical photos. Below the video is the text: 'Charting the health of 14,500 families in the Bristol area to improve the health of future generations.' To the right of the video is a 'Popular links' section with links: 'Submit/amend a research proposal', 'Book now for Focus@24+', 'Update your contact details', 'Explore the Museum of Life', and 'Complete your questionnaire'. At the bottom are three featured sections: 'Participants' with a photo of three young women and a link 'Book now for Focus@24+', 'Researchers' with a photo of three adults and a link 'Access our data', and 'Media' with a photo of a man being interviewed and a link 'Visit the Media section'.

ALSPAC ADMINISTRATIVE ARCHIVE PROJECT

Project background

- We gained funding from the Wellcome Trust to catalogue the administrative archive.
- Scoping survey 2011. Which resulted in a Wellcome Trust funded project from Sept 2015 to Sept 2017 (being extended to March 2018)

ALSPAC ADMINISTRATIVE ARCHIVE PROJECT

Work done so far

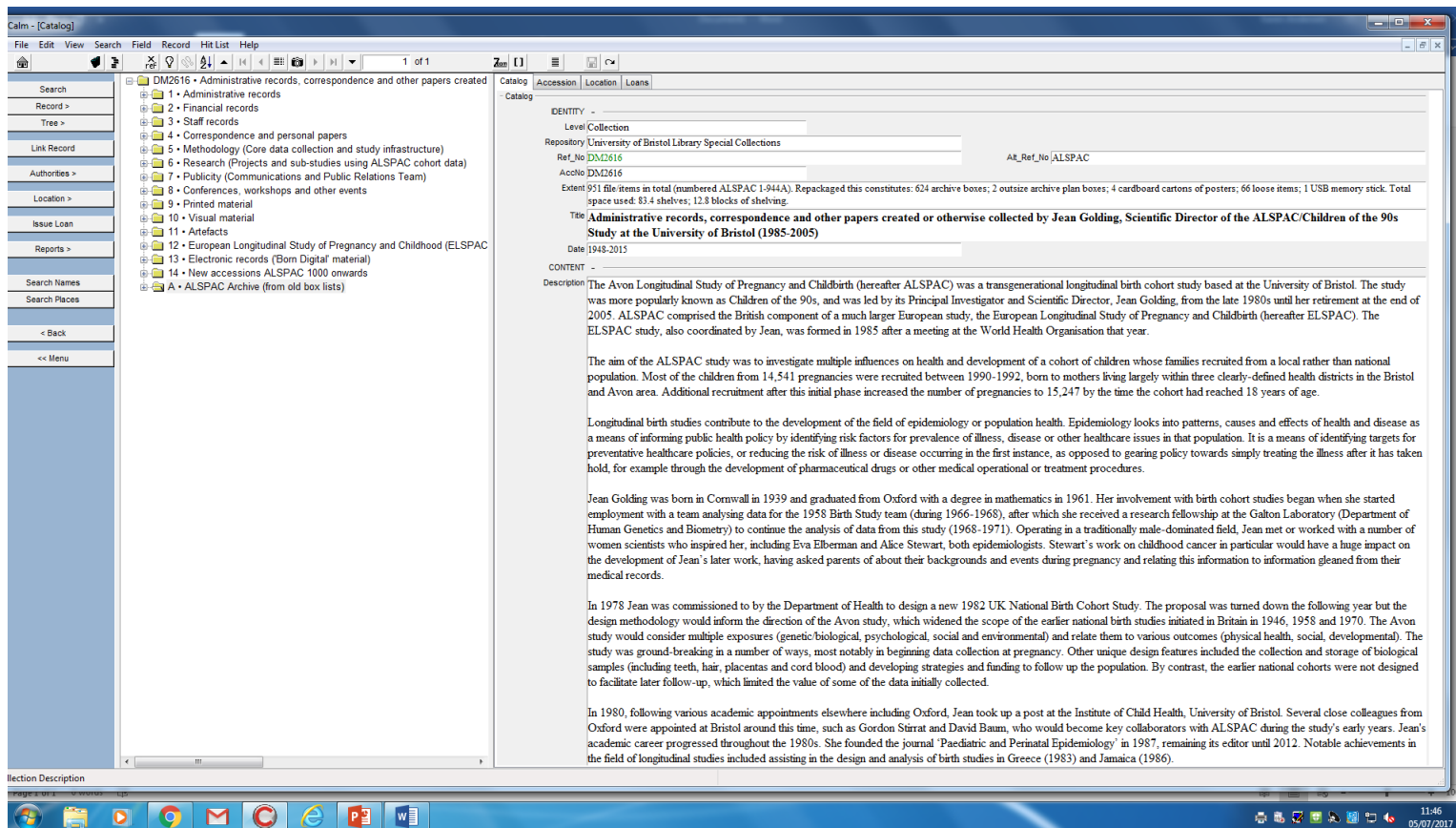
- Negotiated a service level agreement with the ALSPAC Project
- Taken custody of most pre-2005 administrative records (1002 boxes, 950 of which are within scope of the listing project)
- Undertaken preliminary preservation survey, re-boxing and re-packaging

ALSPAC ADMINISTRATIVE ARCHIVE PROJECT

Work done so far (contd)

- Established the main archive series and sub-series
- Description of all records entered in Calm
- Detailed description of 370 boxes completed
- Digitised Newsletters for online access

ALSPAC ADMINISTRATIVE ARCHIVE PROJECT



The screenshot displays a library catalog interface for the University of Bristol. The left sidebar shows a search tree with categories like Administrative records, Financial records, Staff records, etc. The main content area shows the record for 'DM2616 • Administrative records, correspondence and other papers created or otherwise collected by Jean Golding, Scientific Director of the ALSPAC/Children of the 90s Study at the University of Bristol (1985-2005)'. The record includes details such as the repository (University of Bristol Library Special Collections), accession number (DM2616), and a detailed description of the archive's contents and significance.

DM2616 • Administrative records, correspondence and other papers created or otherwise collected by Jean Golding, Scientific Director of the ALSPAC/Children of the 90s Study at the University of Bristol (1985-2005)

Level/Collection: University of Bristol Library Special Collections

RefNo: DM2616

AccNo: DM2616

Extent: 951 file items in total (numbered ALSPAC 1-944A). Repackaged this constitutes: 624 archive boxes; 2 outside archive plan boxes; 4 cardboard cartons of posters; 66 loose items; 1 USB memory stick. Total space used: 83.4 shelves; 12.8 blocks of shelving.

Title: Administrative records, correspondence and other papers created or otherwise collected by Jean Golding, Scientific Director of the ALSPAC/Children of the 90s Study at the University of Bristol (1985-2005)

Date: 1948-2015

CONTENT:

Description: The Avon Longitudinal Study of Pregnancy and Childbirth (hereafter ALSPAC) was a transgenerational longitudinal birth cohort study based at the University of Bristol. The study was more popularly known as Children of the 90s, and was led by its Principal Investigator and Scientific Director, Jean Golding, from the late 1980s until her retirement at the end of 2005. ALSPAC comprised the British component of a much larger European study, the European Longitudinal Study of Pregnancy and Childbirth (hereafter ELSPEC). The ELSPEC study, also coordinated by Jean, was formed in 1985 after a meeting at the World Health Organisation that year.

The aim of the ALSPAC study was to investigate multiple influences on health and development of a cohort of children whose families recruited from a local rather than national population. Most of the children from 14,541 pregnancies were recruited between 1990-1992, born to mothers living largely within three clearly-defined health districts in the Bristol and Avon area. Additional recruitment after this initial phase increased the number of pregnancies to 15,247 by the time the cohort had reached 18 years of age.

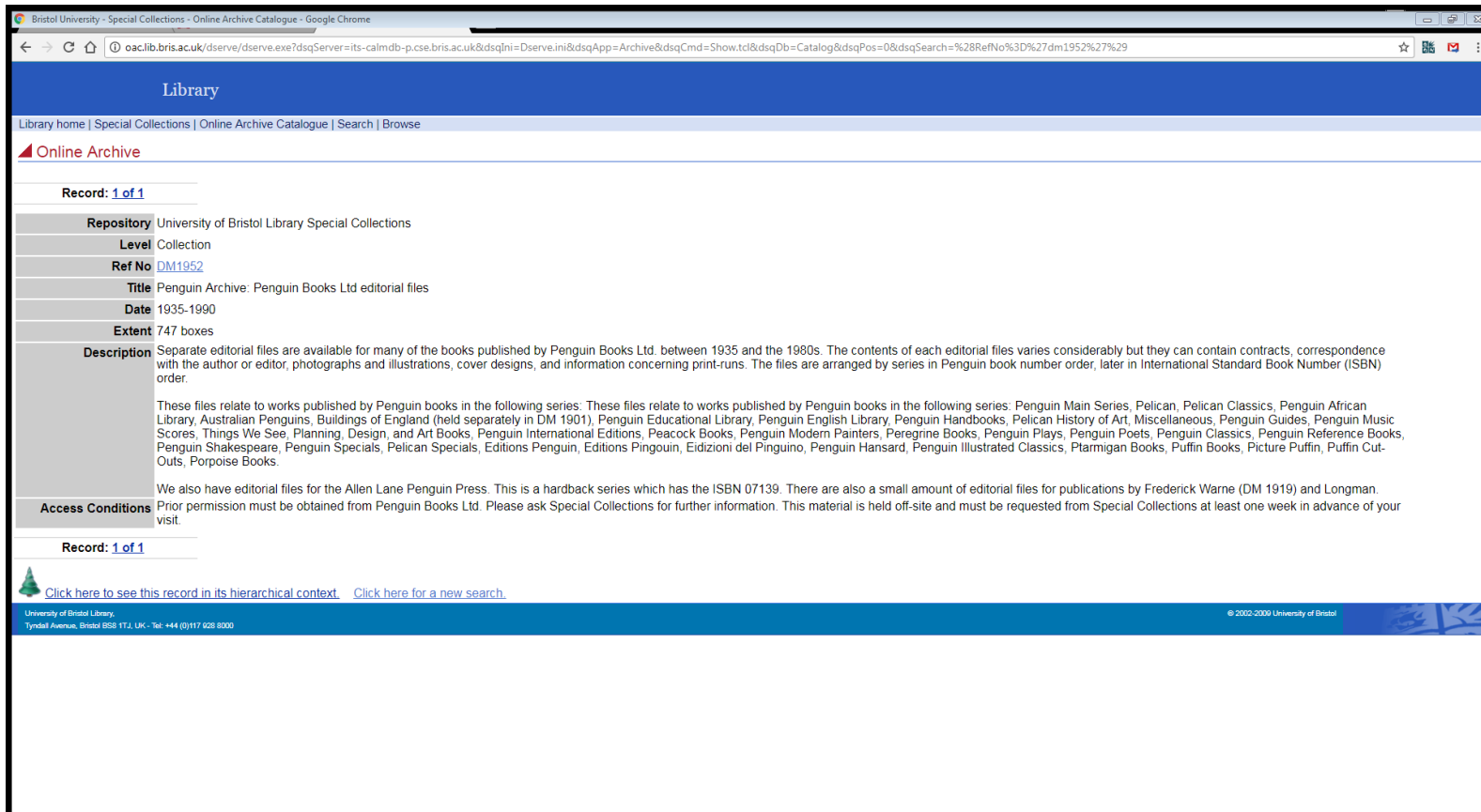
Longitudinal birth studies contribute to the development of the field of epidemiology or population health. Epidemiology looks into patterns, causes and effects of health and disease as a means of informing public health policy by identifying risk factors for prevalence of illness, disease or other healthcare issues in that population. It is a means of identifying targets for preventative healthcare policies, or reducing the risk of illness or disease occurring in the first instance, as opposed to gearing policy towards simply treating the illness after it has taken hold, for example through the development of pharmaceutical drugs or other medical operational or treatment procedures.

Jean Golding was born in Cornwall in 1939 and graduated from Oxford with a degree in mathematics in 1961. Her involvement with birth cohort studies began when she started employment with a team analysing data for the 1958 Birth Study team (during 1966-1968), after which she received a research fellowship at the Galton Laboratory (Department of Human Genetics and Biometry) to continue the analysis of data from this study (1968-1971). Operating in a traditionally male-dominated field, Jean met or worked with a number of women scientists who inspired her, including Eva Elberman and Alice Stewart, both epidemiologists. Stewart's work on childhood cancer in particular would have a huge impact on the development of Jean's later work, having asked parents of about their backgrounds and events during pregnancy and relating this information to information gleaned from their medical records.

In 1978 Jean was commissioned to by the Department of Health to design a new 1982 UK National Birth Cohort Study. The proposal was turned down the following year but the design methodology would inform the direction of the Avon study, which widened the scope of the earlier national birth studies initiated in Britain in 1946, 1958 and 1970. The Avon study would consider multiple exposures (genetic/biological, psychological, social and environmental) and relate them to various outcomes (physical health, social, developmental). The study was ground-breaking in a number of ways, most notably in beginning data collection at pregnancy. Other unique design features included the collection and storage of biological samples (including teeth, hair, placentas and cord blood) and developing strategies and funding to follow up the population. By contrast, the earlier national cohorts were not designed to facilitate later follow-up, which limited the value of some of the data initially collected.

In 1980, following various academic appointments elsewhere including Oxford, Jean took up a post at the Institute of Child Health, University of Bristol. Several close colleagues from Oxford were appointed at Bristol around this time, such as Gordon Stirrat and David Baum, who would become key collaborators with ALSPAC during the study's early years. Jean's academic career progressed throughout the 1980s. She founded the journal 'Paediatric and Perinatal Epidemiology' in 1987, remaining its editor until 2012. Notable achievements in the field of longitudinal studies included assisting in the design and analysis of birth studies in Greece (1983) and Jamaica (1986).

ALSPAC ADMINISTRATIVE ARCHIVE PROJECT



Bristol University - Special Collections - Online Archive Catalogue - Google Chrome

oac.lib.bris.ac.uk/dserve/dserve.exe?dsqServer=its-calmdb-p.cse.bris.ac.uk&dsqIni=Dserve.ini&dsqApp=Archive&dsqCmd=Show.tcl&dsqDb=Catalog&dsqPos=0&dsqSearch=%28RefNo%3D%27dm1952%27%29

Library

Library home | Special Collections | Online Archive Catalogue | Search | Browse

Online Archive

Record: 1 of 1

Repository	University of Bristol Library Special Collections
Level	Collection
Ref No	DM1952
Title	Penguin Archive: Penguin Books Ltd editorial files
Date	1935-1990
Extent	747 boxes
Description	<p>Separate editorial files are available for many of the books published by Penguin Books Ltd. between 1935 and the 1980s. The contents of each editorial files varies considerably but they can contain contracts, correspondence with the author or editor, photographs and illustrations, cover designs, and information concerning print-runs. The files are arranged by series in Penguin book number order, later in International Standard Book Number (ISBN) order.</p> <p>These files relate to works published by Penguin books in the following series: These files relate to works published by Penguin books in the following series: Penguin Main Series, Pelican, Pelican Classics, Penguin African Library, Australian Penguins, Buildings of England (held separately in DM 1901), Penguin Educational Library, Penguin English Library, Penguin Handbooks, Pelican History of Art, Miscellaneous, Penguin Guides, Penguin Music Scores, Things We See, Planning, Design, and Art Books, Penguin International Editions, Peacock Books, Penguin Modern Painters, Peregrine Books, Penguin Plays, Penguin Poets, Penguin Classics, Penguin Reference Books, Penguin Shakespeare, Penguin Specials, Pelican Specials, Editions Penguin, Editions Pinguin, Eidizioni del Pinguino, Penguin Hansard, Penguin Illustrated Classics, Ptarmigan Books, Puffin Books, Picture Puffin, Puffin Cut-Outs, Porpoise Books.</p> <p>We also have editorial files for the Allen Lane Penguin Press. This is a hardback series which has the ISBN 07139. There are also a small amount of editorial files for publications by Frederick Warne (DM 1919) and Longman.</p>
Access Conditions	Prior permission must be obtained from Penguin Books Ltd. Please ask Special Collections for further information. This material is held off-site and must be requested from Special Collections at least one week in advance of your visit.

Record: 1 of 1

[Click here to see this record in its hierarchical context.](#) [Click here for a new search.](#)

University of Bristol Library,
Tyndall Avenue, Bristol BS8 1TJ, UK - Tel: +44 (0)117 928 8000

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Main issues:

- No records management – e.g. expense claims/employee performance records kept beyond their retention periods
- Access controls – complex “Data Matrix” (based on document security markings) drawn up by ALSPAC is difficult to apply in practice
- The “Data Matrix” has “Public” and “Open” classifications, but ALSPAC want Special Collections’ “Closed” status to apply even to these

ALSPAC ADMINISTRATIVE ARCHIVE PROJECT

Main issues (contd):

- Content of material still to be listed (mostly correspondence) – attempting to make this accessible by redaction/removal of sensitive data
- Participant anonymity is guaranteed by the ALSPAC Project, but some participants have “gone public”
- The “Data Matrix” does not go beyond classification based on current access – as Special Collections’ ultimate goal is make the all the records accessible we need to determine appropriate closure periods

ALSPAC ADMINISTRATIVE ARCHIVE PROJECT

Addressing the issues:

- Negotiated the weeding out of records of temporary administrative value only
- Applied Special Collections simple Open/Closed access controls as well as the “Data Matrix”
- Negotiating open access for non-sensitive material
- Negotiating revision of “Data Matrix” and attempting to apply it at sub-series level

ALSPAC ADMINISTRATIVE ARCHIVE PROJECT

Addressing the issues (contd):

- Continue listing in detail to flag sensitive material/discover participant data, but no more redactions
- Established clear guideline that records containing participant data are to be returned to ALSPAC
- Attempting to determine appropriate closure periods for sensitive classes of records. Liaison with colleagues working on archives of other cohort projects – attending this workshop!

ALSPAC ADMINISTRATIVE ARCHIVE PROJECT

Going forward

- Finish cataloguing
- Attach Newsletters to Calm descriptions
- More work on born-digital records
- Establish access protocols for researchers
- Launch the catalogue by March 2018