

ALSPAC Board

Terms of Reference

1. Introduction

- 1.1 The role of the ALSPAC Board is to provide oversight of the ALSPAC Executive (AE). The Board will support the Principal Investigator through the monitoring of operational activity, governance mechanisms, objectives and deliverables and output and impact as well as advising on scientific strategy. This is achieved through the examination of regular management reports on operational and scientific activity.
- 1.2 If a problem or issue arises that requires additional deliberation and/or adjudication by an independent external body, the Board will seek advice from the Independent Scientific Advisory Board (ISAB).

2. Membership

- 2.1 The Board meetings will be chaired by Professor Matt Hickman, Head of Population Health Science (PHS and Deputy Head of [Bristol Medical School \(PHS\)](#)
- 2.2 Members are drawn from the University of Bristol though if expertise is required then this will be sought from elsewhere. Members are individuals who have an expertise in key areas of ALSPAC activity such as new data and sample collection, linkage, data management and sample management. Members of the ALSPAC Executive will attend Board meetings as observers. The Board requires the presence of at least one practising clinician.

Title	Name
Professor of Medical Statistics and Epidemiology, Bristol Medical School (PHS)	Jonathan Sterne
Professor of Medical Statistics, Bristol Medical School (PHS)	Kate Tilling
Professor of Health and Anthropology/Director of Elizabeth Blackwell Institute, Bristol Medical School (THS)	Rachael Gooberman-Hill
Professor in Diabetes and Metabolic Endocrinology, Bristol Medical School (THS)	Julian Hamilton Shield
Professor of Primary Care Health Services Research, Bristol Medical School (PHS)	Tim Peters
Professor of Health and Biomedical Informatics, Bristol Medical School (PHS)	Tom Gaunt
Senior Research Fellow, Bristol Medical School (PHS)	Gib Hemani
Head of Finance Business Partnering, Finance Services	Sarah Everett Cox
Professor of Epigenetic Epidemiology, Bristol Medical School (PHS)	Caroline Relton
Professor in Clinical Epidemiology and Primary Care & Joint Head of CAPC, Bristol Medical School (PHS)	John Macleod
Reader in Epidemiology and Medical Statistics, Bristol Medical School (PHS)	Laura Howe
Gestetner Professor of Translational Dementia Research	Pat Keyhoe

Professor of Biological Psychology, School of Psychological Science	Marcus Munafo
Academic Clinical Lecturer in Haematology, School of Cellular and Molecular Medicine	Sarah Westbury
Senior Lecturer in Management, Department of Management/Head of Policy Bristol	Patricia Gaya
Consultant in Public Health, Bristol City Council and Consultant Senior Lecturer, Bristol Medical School (PHS)	Jo Williams
Participant Representatives	TBC

- 2.3 It is expected that members would make every effort to attend the meetings. Members may allow deputies to attend in their place, but a minimum of two meetings per year is required for members
- 2.4 Board meetings are structured around the review of management reports. Members are expected to undertake regular review of reports and feedback to the Board either in person at the meeting or via written feedback.
- 2.5 A quorum exists where there is a minimum of five Board members in addition to members of the AE
- 2.5 Members are appointed for the funding period (up to July 2024). Members are expected to fully understand and enact the recognised duties and responsibilities of their role.
- 2.6 The Chair, in consultation with the Board, will be responsible for reviewing membership and appointing new members.
- 2.7 The Board may refer to the ALSPAC Clinical Advisory Group for matters requiring clinical input
- 2.6 A representative from ISAB may attend any meeting.

3. Remit

- 3.1 The remit and work programme of the Board incorporates:
 - Oversight of the AE, ensuring the efficient and effective management of ALSPAC; review of management reports as detailed below:

Management Report	Reviewer
Clinic Report	Laura Howe
Sub Studies Report	Sarah Westbury
Remote Data report	Marcus Munafo
Data Linkage Report	John Macleod
BBL Report	Caroline Relton
Data and Sample Access and Metrics Report	Jonathan Sterne
Systems Architecture Report	Tom Gaunt, Gib Hemani
Overview Data Collection/preparation Report	Julian Hamilton Shield

Operations Summary Report	Change management (all) Finance (Sarah Everett Cox) Grant tracking (Tim Peters) Information security (John Macleod) Issues and risks (Pat Kehoe) Communications/participation (Patricia Gaya, Jo Williams) Ethics (Rachael Gooberman Hill)
Publications Report	Kate Tilling
Wellcome Annual Report	All

- Strategic review of the progress of each programme of work, including the risks and future plans
- Resolution of issues that have been referred up by the AE
- Support to the Principal Investigator with scientific strategy.
- Provide expert clinical advice to the AE where necessary

4. Objectives and Responsibilities

4.1 Strategic oversight of ALSPAC:

- Ensure ALSPAC is run in accordance with agreed policies and procedures
- Review reports prepared by the AE on progress and activity in ALSPAC
- Regular reports submitted to the Board will cover progress and/or activity regarding clinic activity, data preparation and legacy data project, bioresources, issue log and risk register, publications, data access, funding, participation/engagement and communication activities
- Review, and where necessary recommend actions to increase, the effectiveness and impact of the AE
- Offer support, advice and guidance to the AE
- Monitor complaints from participants, researchers and other stakeholders
- Oversee ALSPAC’s interface with all stakeholders including its external image both publicly and professionally
- Initiate appropriate processes if rules or regulations are breached
- Promote cross study collaborations
- Oversee the funders mid-term review of ALSPAC in 2022/3

4.2 Strategic review of core components:

- Initiate, produce, regularly review, update and where necessary recommend changes to the ALSPAC core components
- Review regular reports on these work programmes ensuring that any deliverables or actions are being met and that any corrective action suggested is appropriate and likely to give the desired result
- Offer advice on new strategies to contain risks and enhance outcomes of all work programs

4.3 Resolving issues that have been referred up by the AE:

- Provide issue resolution referred to the Board by the AE
- Monitor issues referred up and where relevant offer advice on ways of reducing future issues arising

- 4.4 Supporting the Principal Investigator with scientific strategy:
 - a. Support the Principal Investigator in the development of a strategic plan for ALSPAC after the current award ends in 2024
 - b. Keep abreast of developments in scientific areas and advise on ways to maximise scientific potential of the study
- 4.5 Provision of expert clinical advice to the AE as requested:
 - a. Clinical members of Board may be called upon to provide clinical advice to the AE as and when is necessary
 - b. The Board may refer to the ALSPAC Clinical Advisory Group where necessary
- 4.6 Provision of other specific advice to the AE as requested:
 - a. Members of Board may be called upon to provide specific advice to the AE as and when is necessary

5. Meetings

- 5.1 The Board meets once per quarter
- 5.2 The chair can call an extraordinary meeting or initiate an online discussion to discuss urgent business, should the need arise.

6. Minutes and Reporting

- 6.1 The minutes of the meetings will be circulated to Board members and observers only.

7. Constitution

- 7.1.1 These terms of reference were approved by the ALSPAC Board on the 19th December 2019.