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.

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

<table>
<thead>
<tr>
<th>Management Report</th>
<th>Reviewer</th>
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<tbody>
<tr>
<td>Clinic Report</td>
<td>Laura Howe</td>
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<tr>
<td>Sub Studies Report</td>
<td>Sarah Westbury</td>
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<tr>
<td>Remote Data report</td>
<td>Marcus Munafo</td>
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<td>Data Linkage Report</td>
<td>John Macleod</td>
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<tr>
<td>BBL Report</td>
<td>Caroline Relton</td>
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<tr>
<td>Data and Sample Access and Metrics Report</td>
<td>Jonathan Sterne</td>
</tr>
<tr>
<td>Systems Architecture Report</td>
<td>Tom Gaunt, Gib Hemani</td>
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<tr>
<td>Overview Data Collection/preparation Report</td>
<td>Julian Hamilton Shield</td>
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4. Objectives and Responsibilities

4.1 Strategic oversight of ALSPAC:

a. Ensure ALSPAC is run in accordance with agreed policies and procedures
b. Review reports prepared by the AE on progress and activity in ALSPAC
c. 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
d. Review, and where necessary recommend actions to increase, the effectiveness and impact of the AE
e. Offer support, advice and guidance to the AE
f. Monitor complaints from participants, researchers and other stakeholders
g. Oversee ALSPAC’s interface with all stakeholders including its external image both publicly and professionally
h. Initiate appropriate processes if rules or regulations are breached
i. Promote cross study collaborations
j. Oversee the funders mid-term review of ALSPAC in 2022/3

4.2 Strategic review of core components:

a. Initiate, produce, regularly review, update and where necessary recommend changes to the ALSPAC core components
b. 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
c. 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:

a. Provide issue resolution referred to the Board by the AE
b. 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.