ALSPAC Board

Terms of Reference

1. Introduction

1.1 The ALSPAC Board was set up in June 2017 following a management restructure of ALSPAC. The role of the Board is to provide oversight of the ALSPAC Executive (AE) and support the Principal Investigator and Scientific Director with scientific strategy.

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 ISAB.

2. Membership

2.1 The Board meetings will be chaired by Professor Matt Hickman.

2.2 Members are made up of those responsible for the delivery of work programmes under the current strategic award (see below) and independent representatives of key scientific groups. 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>Strategic Award 2014 – 2019 Work Programme</th>
<th>Lead</th>
</tr>
</thead>
<tbody>
<tr>
<td>B1 SA Research Infrastructure inc data access</td>
<td>Lynn Molloy</td>
</tr>
<tr>
<td>B2 SA Lab Infrastructure</td>
<td>Sue Ring</td>
</tr>
<tr>
<td>B3 SA Cohort maintenance</td>
<td>Lynn Molloy</td>
</tr>
<tr>
<td>B4 SA Linkage</td>
<td>John Macleod</td>
</tr>
<tr>
<td>B5 SA Data collection in YP</td>
<td>Nic Timpson</td>
</tr>
<tr>
<td>B6 SA G2</td>
<td>Debbie Lawlor</td>
</tr>
<tr>
<td>B7 SA GWAS consolidation</td>
<td>Nic Timpson and Gib Hemani</td>
</tr>
<tr>
<td>Scientific direction</td>
<td>George Davey Smith</td>
</tr>
<tr>
<td>Data Management</td>
<td>Kate Northstone</td>
</tr>
<tr>
<td>Mothers</td>
<td>Debbie Lawlor</td>
</tr>
<tr>
<td>Fathers</td>
<td>TBC</td>
</tr>
<tr>
<td>Siblings</td>
<td>TBC</td>
</tr>
<tr>
<td>Grandparents</td>
<td>TBC</td>
</tr>
<tr>
<td>Bioinformatics</td>
<td>Tom Gaunt</td>
</tr>
<tr>
<td>Change management</td>
<td>Lynn Molloy</td>
</tr>
<tr>
<td>Policy/Impact</td>
<td>Lynn Molloy</td>
</tr>
<tr>
<td>Clinical representative</td>
<td>Julian Hamilton-Shield</td>
</tr>
<tr>
<td>BRC representative</td>
<td>Jonathan Sterne</td>
</tr>
</tbody>
</table>
2.3 It is expected that members would make every effort to attend the meetings.

2.4 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 period of the Strategic Award (up to March 2019). 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 the Independent Scientific Advisory Board (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.
- 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 Scientific Director and Principal Investigator with scientific strategy.
- Provide expert clinical advice to the AE where necessary.

4. Objectives and Responsibilities

4.1 Strategic oversight of ALSPAC:

a. Ensure ALSPAC is run in accordance with agreed policies and procedures.

b. Periodically 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. Oversee the provision of support for clinical safety of participants and the safeguarding of vulnerable individuals.

g. Monitor complaints from participants, researchers and other stakeholders.
h. Oversee ALSPAC’s interface with all stakeholders including its external image both publically and professionally
i. Initiate appropriate processes if rules or regulations are breached

4.2 Strategic review of work programmes:

a. Initiate, produce, regularly review, update and where necessary recommend changes to the ALSPAC work programme plan
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 and Scientific Director with scientific strategy:

a. Support the Principal Investigator and Scientific Director in the development a strategic plan for ALSPAC after the current strategic award ends in 2019
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 every quarter starting from September 2017.

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 8 October 2018.