ALSPAC Clinical Advisory Group

Terms of Reference

1. Introduction

1.1 ALSPAC undertakes new data and sample collection on study participants, often involving clinically relevant measurements. These include the collection of biological samples, scans and physical measures such as blood pressure. These studies may be undertaken on the full sample or on a subgroup selected on the basis of certain characteristics, including specific diseases.

1.2 The Clinical Advisory Group will not provide clinical advice to participants and they are not responsible for interpreting or acting on ALSPAC clinical measures. The responsibility for developing safe protocols/ SOP for incidental findings and results is the responsibility of research team submitting each new proposal and will be subject to the usually ethical and regulatory approvals. The role of the group is to provide expert clinical perspectives to the PI and will not impact on members medical indemnity.

1.3 A clinical ALSPAC Board member will provide oversight for the Clinical Advisory Group and will report to the Board on any issues of importance arising from the activities of the Group.

2. Remit

2.1 The remit and work programme of the Clinical Advisory Group:

- Provide opinion from a clinical perspective to the PI on matters relating to clinical measurements.
- Consider and review standard operating procedures from researchers in relation incidental findings and feedback of these incidental findings to study participants.
- Consider questions from ALSPAC Board relating to clinical matters.
- Provide opinion from a clinical perspective to the PI on what clinical measures should be included in future data and sample collection sweeps.
- Provide opinion from a clinical perspective to the ALSPAC Board on clinical activities, ensuring that they are compliant with standards as determined by external regulatory bodies such as the General Medical Council (GMC), General Dental Council (GDC) or equivalent.

3. Membership

3.1 The tenure of the Chair of the ALSPAC Clinical Advisory Group will initially be 12 months, although this can be extended beyond this. The Chair will escalate any issues to the clinical representative on the ALSPAC Board.

3.2 Members of the Clinical Advisory Group will be healthcare professionals with full professional registration in the UK who currently provide patient care alongside their research interests. Typically, the panel will include doctors in primary and secondary care settings, but membership is also open to dentists, midwives, nurses, radiographers, physiotherapists, and other healthcare professionals who meet this definition.

3.3 The tenure of membership will initially be 12 months, although this can be extended beyond this.

3.3 The Chair will have the responsibility for the timetable, agenda and conduct of meetings and for maintaining a record of proceedings. ALSPAC will provide administrative support to the Chair for these responsibilities.

4. Meetings

4.1 The ALSPAC Clinical Advisory Group will normally meet quarterly, although an extraordinary meeting may be called to consider any urgent matters at the request of the PI.

4.2 Meetings can be held physically or virtually.

5. Minutes and Reporting

5.1 Papers for the meeting will be sent out electronically no less than one week prior to the meeting date.

5.2 The minutes of the meetings will be circulated to the Clinical Advisory Group members.

6. Constitution

6.1 These terms of reference were approved by the ALSPAC Board on the 21 April 2023.