



UNIVERSITY OF ABERDEEN

Aberdeen Maternity & Neonatal Databank Committee Terms of Reference

1. Constitution

The University of Aberdeen and NHS Grampian established the Steering Committee for the Aberdeen Maternity and Neonatal Databank (AMND) to act as guardians of the data. Its role and responsibilities are delegated in these terms of reference.

2. Terms of Reference

2.1 Aims and purpose

To provide assurances to the University of Aberdeen and NHS Grampian that the AMND is governed robustly and that there are effective systems and processes used for the collection, storage and use of clinical data.

2.2 Objectives

The primary objective of the AMND Committee is to ensure that systems for data collection, storage and use are effective and robust. The systems include, but are not limited to:

- Consistent and reliable data coding and entry
- Secure storage of data
- Timely and accurate retrieval of data for audit and research purposes
- Quality assurance
- Protect the identity and safeguard the rights of those whose data are stored within the AMND.
- Develop a strategy for the sustainability and financial viability of the AMND.

In addition the Committee will:

- Peer review all applications for data extraction from AMND and make a decision as to whether the data should be released or not.
- Advise on ethical and methodological issues relating to applications, such as study design, data extractions, data linkage, analysis and feasibility of the study.
- Advise those requesting data to write to the relevant NHS Ethics Committee to establish if formal ethical approval is needed.
- Ask researchers to sign a data release form stating that they will adhere to all existing standards of research governance within their host organisation.
- Review security measures and ensure that mechanisms for safeguarding the confidentiality of the data are effective.
- Respond to breaches of anonymity or confidentiality.
- Monitor progress against agreed objectives by requesting a copy of the final report/thesis/publication.

3. Membership

The composition of the committee should include representation from the University of Aberdeen (minimum of 3 members, including one from the Institute of Applied Health Sciences), NHS Grampian (minimum of 3 obstetric consultants, one neonatologist and one midwife) and a member of the public.

The Chair (an NHS Grampian employee) will be appointed using a formal selection process

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by the Committee and will serve for a period of 5 years.

4. Quorum

Business will only be conducted if the meeting is quorate. The meeting will be quorate with four full committee members, including at least one from UOA and one from NHS Grampian, being present.

5. Attendance by members

The Chair will be expected to attend 100% of meetings. Other members will be expected to attend at least 75% of meetings per annum.

6. Attendance by others

The Committee can co-opt for others to attend the meeting when appropriate.

7. Accountability and reporting arrangements

The Committee will be accountable and report to the research governance committee at the Institute of Applied Health Sciences of the University of Aberdeen.

8. Frequency and recording of meetings

The Committee will meet four times per year. Additional meetings may be arranged to support the effective functioning of the AMND.

An agenda and papers will be sent to Committee members no later than one week ahead of a scheduled meeting. Unapproved notes/minutes of the meeting will be taken and sent to members no later than two weeks after a meeting has been held. These will be considered for approval by the Committee at the next meeting.

9. Monitoring effectiveness

An annual report will be produced at the end of the financial year to assess the work of the AMND Steering Committee in terms of research projects approved, quality assurance of data collection and financial statements Any emerging governance issues will be discussed and noted.

10. Review

The Committee will review its terms of reference on an annual basis.