**Aberdeen Maternity and Neonatal Databank**

The Steering Committee requires the following details of proposed research using the Databank.

# Name of researcher(s) and collaborators (Please indicate who will have access to the data):

Anthony S Chapman (PhD student with access to data)

Dr Steve Turner (Supervisor)

Dr Lorna Aucott (Supervisor)

Dr Wei Pang (Supervisor)

# Institution and address:

University of Aberdeen

King's College, Aberdeen AB24 3FX

**Title of Research** (if this is a research proposal, please enclose copies of protocol):

Linkage of AMND and PIS databases

**Source of Funding** (if applicable):

FARR Institute of Research

**Linkage Requirements:Do you plan to link with other registers? No☐** **Yes X**

|  |
| --- |
| If data linkage is required please provide details below:  We plan to link AMND to PIS in order to see whether small fetuses grow up to be people with non-communicable diseases (identified by prescribed medication). |

**Has NHS Ethical Approval been sought? No X** **(but will be sought)**

## Data requested:

Time period of data requested: from 1997 onwards (ie when chi numbers are present)

**Inclusion/exclusion criteria and data format:**

Singletons only (included) **X**

Multiples and singletons **☐**

Twins only **☐**

Parous only **☐**

Prims only **☐**

Intergenerational **☐**

One row per woman **☐** / One row per pregnancy **X**

**Please provide more details on characteristics of population to be studied:**

|  |
| --- |
| *For example women who delivered their second baby beyond 20 weeks gestation between 1990 and 2012*  All pregnancies which resulted in live born infant, excluding multiple pregnancies |

Data will be provided as SPSS file unless otherwise stated

**Details of where the data will be stored and for how long:**

NHS Grampian **☐** Years: Months:

Safe haven **X** Years: **5** Months: **0**

University of Aberdeen **☐** Years: Months:

Other (*please specify below)***☐** Years: Months:

|  |
| --- |
|  |

**Data Specifications**:

This is a list of variables commonly requested. Additional variables may be available for a limited time period. Please note that the accompanying protocol should justify the use of all variables requested.

*Please add more columns if more than one pregnancy is required and indicate what details are required for each pregnancy (one column per pregnancy)*

|  |  |
| --- | --- |
| **Variable** | **Required** |
| Study number (Unique identifier for each woman) | Routinely provided |
| Age at delivery | X |
| Parity | X |
| Pregnancy number | X |
| Height | X |
| Weight (First weight at antenatal visit <20 weeks) | X |
| Gestation at booking | X |
| Blood Group |  |
| Smoking | X |
| Residence |  |
| Husband's Social class |  |
| Own Social class |  |
| Deprivation category | X |
| Scottish Indices of Multiple Deprivation |  |
| Marital status |  |
| Threatened miscarriage |  |
| Hypertensive disorders (Mild, moderate -severe, eclampsia, other) |  |
| Antepartum haemorrhage (placenta praevia, abruption, other) |  |
| Type of labour (Spontaneous, induced, Elective caesarean section) | X |
| Mode of delivery (vaginal, forceps, vacuum extraction, c- section) |  |
| Gestation at delivery in weeks | X |
| Outcome of baby (live birth, stillbirth, multiple birth, neonatal death) |  |
| Outcome of delivery (live birth, stillbirth, multiple birth) |  |
| Outcome of gynae event (spontaneous abortion, missed abortion, induced abortion, ectopic pregnancy, mole, choriocarcinoma) |  |
| Birthweight | X |
| Standardised birthweight score | X |
| Admission to neonatal unit |  |
| Preterm pre-labour rupture of membrane |  |
| Blood loss at delivery |  |

**Please list any other variables you would like to request in the table below and provide additional information if necessary** (please add more rows if required):

|  |  |
| --- | --- |
| **Variable** | **Additional information** |
| Child CHI number |  |
| Date of LMP |  |
| Date of birth |  |
| Date of first trimester scan |  |
| First trimester scan measurements |  |
| Date of second trimester scan |  |
| Second trimester scan measurements |  |
| Date of third trimester scan |  |
| Third trimester scan measurements |  |
| Crown heel length |  |
| Occipito frontal circumference |  |
| Maternal identifier to allow linkage to other pregnancies |  |

**The AMND has past medical history recorded. Please indicate the specific diseases of interest if required** (please add more rows if required):

|  |  |  |  |
| --- | --- | --- | --- |
| **Name of disease** | **ICD-9 Codes** | **Period required** | |
| **Pre-pregnancy** | **Current pregnancy** |
| Asthma | 493 | Yes please | Yes please |
| Epilepsy | 345 | Yes please | Yes please |
| Type I diabetes | 250 | Yes please | Yes please |
| Attention Deficit Hyperactivity Disorder | 314 | Yes please | Yes please |

**Drugs** (please add more rows if required):

|  |  |
| --- | --- |
|  | **Generic name** |
| Drug A |  |
| Drug B |  |
| Drug C |  |

I agree to abide by the regulations for access to the Databank as set out by the Databank Steering Committee **X**

|  |  |
| --- | --- |
| Signature: | Date: |

**Named individuals requiring access to data set:**

1. **\_Anthony Chapman\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**
2. **\_Dr Steve Turner \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**
3. **\_\_Lorna Aucott\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**
4. **\_\_DASH staff\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Regulations for access have been agreed as follows:**

1. All requests for access must be made through the Aberdeen Maternity and Neonatal Databank Steering Committee (“Committee”) in order to ensure that the proposed use of the data conforms to accepted scientific standards in terms of methodology, confidentiality and ethics.
2. Access will only be available to applicants who, in the opinion of the Committee are bona fide researchers.
3. Applicants will be required to complete and sign the AMND application form, and forward a copy of any correspondence or letter of approval from the Ethics Committee.
4. Processing and use of data must comply with the requirements of the Data Protection Act (1998). The following principles must be followed:

* Data access should be restricted to named users (as named above).
* Data should not be transferred to anyone not named above.
* Data should be used for the specified project, if the researcher wishes to use the data for any other purpose, they must re-approach the Committee for approval.
* Data should be stored securely on a networked shared drive which is regularly backed up.

Where there is a requirement to transfer data then it should be sent via nhs.net email or via the University’s zendto service with the attachment password protected.

* Workstations logged into AMND data should not be left unattended and must be password protected.
* Archived data must be accorded the same level of security as when they were in active use – advice on how to archive data appropriately can be sought from the University IT Services.
* Information about the intended destruction of data must be provided to the Committee.
* Records of the destruction of data must be kept for audit purposes and a copy sent to the committee

1. All applicants will be required to forward any relevant manuscripts which use the supplied data to the Committee prior to submission for publication in order to ensure factual accuracy and correct interpretation.
2. All papers, presentations and posts should ensure appropriate acknowledgement of the AMND in line with the format below:

*The Aberdeen Maternity and Neonatal Databank (AMND) related personnel are core funded by the University of Aberdeen. The authors wish to thank (names of individuals) who (what they did) and the Data Management Team, University of Aberdeen for Data Extraction. More information for accessing data from the AMND can be obtained from the AMND website* [*www.abdn.ac.uk/amnd*](http://www.abdn.ac.uk/amnd)*.*

1. Copies of any publications must be sent to the Committee within 3 months of publication.
2. The Committee, as far as possible, will encourage collaborative research with one or more members of the Committee or designated colleagues in order to facilitate accurate use and interpretation of the data.
3. Final reports with a lay summary of the research project using AMND data must be submitted to the Committee within 3 months of completion.
4. Charges for supply of AMND data will depend on several factors:

* origin of the request
* whether there has been a previous extraction for the same project
* the complexity of the extraction requested

Feedback on charges to be levied will be given once the Committee have agreed in principle to the request.

1. Data linkage projects involving AMND data will also be required to work to any other applicable terms of use for example the Grampian Data Safe Haven terms of use or eDRIS terms of use.
2. No attempt shall be made to re-contact participants whose data is included in the AMND.

All enquiries and completed application forms should be addressed to:

Dr Sohinee Bhattacharya

Dugald Baird Centre

University of Aberdeen

Aberdeen Maternity Hospital

Cornhill Rod

Aberdeen

AB25 2ZL

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