Data Resource Profile: Aberdeen Maternity and Neonatal Databank (AMND)

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AMND in a nutshell

- The AMND was set up as a resource for the study of the physiology, pathology and sociology of pregnancy. It is one of the earliest and most comprehensive obstetric databases making it an invaluable resource for lifecourse epidemiology.
- AMND was initiated in 1950 and currently holds data on about 181 145 women with 274 323 pregnancies, 272 449 deliveries and 277 324 babies of which 4120 are twins. Data is also available for 32 681 mother-daughter pairs, 5538 grandmothers and 111 great grandmothers
- Data is collected continuously from medical notes of pregnant women attending Aberdeen Maternity Hospital.
- For a viable pregnancy, AMND includes four mandatory record types, containing data for the patient, pregnancy, delivery and baby. A further 40 optional record types contains clinical details, test results and grouping of complete reproductive histories for individual women and families spanning three generations. Gynaecological record detailing the type of early pregnancy loss and other information about the woman are available for those with a non-viable pregnancy.
- Requests to access the AMND data must be made using the application form which can be downloaded from the AMND webpage (http://www.abdn.ac.uk/iahs/research/obsgynae/amnd/access.php)

Data Resource Basics:

The Aberdeen Maternity and Neonatal Databank (AMND) was initiated in the department of Obstetrics and Gynaecology, University of Aberdeen in 1950, by the late Professor Sir Dugald Baird, in collaboration with the Medical Research Council's (MRC) Medical Sociology Unit. It was originally set up as a resource for the study of the physiology, pathology and sociology of pregnancy but the usefulness of AMND has extended significantly beyond this through linkage with other health and social care records as well as intergenerational and family linkages. Intrauterine exposures can permanently alter physiology and metabolism leading to higher risk of developing some diseases in adulthood as suggested by the Barker Hypothesis.[1] The AMND is an invaluable resource for lifecourse epidemiology especially since it is one of the earliest and most comprehensive obstetric databases. From the year 1950 to the present, this unique database has been recording all the obstetric and fertility-related events occurring in women residing in Aberdeen, Scotland, United Kingdom (UK). The data was initially held on punched cards, computerised in 1970's and subsequently in 1986 it was redeveloped onto a relational database known as Scientific Information Retrieval (SIR). The database was re-platformed in 2007 and is now held in a Microsoft SQL server database with an Access front end. Databank related personnel are core funded by the University of Aberdeen and additional funding from funded projects used to maintain and enhance the databank.

Data resource area and population coverage:

Data is collected from every pregnancy event occurring in Aberdeen Maternity Hospital which is part of the National Health Services (NHS) Grampian. Aberdeen Maternity Hospital is the only maternity hospital in the city of Aberdeen and serves the Grampian region as well as the Northern Isles, Shetland and Orkney for tertiary maternity care. A dedicated midwives' unit also based at the hospital provides shared maternity care for uncomplicated pregnancies. The hospital provides

antenatal and post-natal care with about four to five thousand babies born every year. In addition, an early pregnancy unit based at the hospital manages complications such as miscarriage and other pregnancy loss. The AMND also captures data from these units. The AMND population coverage varies according to different areas. It covers about 99% of Aberdeen and about 97% of the entire Grampian region. This differential coverage is due to a small proportion of home births and deliveries in peripheral hospitals.

Data collection frequency:

The AMND is updated using a Microsoft Access Front end on a daily basis, by up to three concurrent users, with information relating to approximately 100 births every week. Data is collected continuously from medical notes of pregnant women attending Aberdeen Maternity Hospital, with free text being updated to ICD 9 or 10 codes. At the time of writing, data entry is nearly complete for the year 2013 and some progress has been made towards completion of 2014. Currently, the AMND holds information on approximately 181 145 women with 274 323 pregnancies, 272 449 deliveries and 277 324 babies of which 4120 are twins. In terms of intergenerational data, there are at least 32 681 mother-daughter pairs, 5538 grandmothers and 111 great grandmothers.

Measures:

Data from medical notes of all pregnant women are coded and entered onto the AMND by dedicated and trained clerical staff. The completeness of data entry is checked at the end of each year with the NHS hospital returns. There are several validity checks incorporated within the database to ensure against invalid data entry. The accuracy of data entry is checked regularly for subsets of records using case note reviews. The AMND is such a large database that it is practically impossible to list all the variables that are recorded (See Figure 1). It includes about 45 record types

for a viable pregnancy, four of which are mandatory and contain data for the patient, pregnancy, delivery and baby and a further 40 optional record types used for clinical details, test results and grouping of complete reproductive histories for individual women and families spanning three generations. A sample of the items recorded within the mandatory record types are listed in Table 1. For those with a non-viable pregnancy, there is a record detailing the type of early pregnancy loss and other information about the woman. Additional variables available for some but not all of the time period are listed in Table 2.

It is also possible to link individuals from the AMND with other registers using either a unique identifier (Community Health Index) available for each individual registered with a general practice in Scotland or probability matching on name, date of birth and post code. For example, individual records from the AMND have been linked previously with the Scottish Morbidity Record Systems to assess subsequent mortality and hospital admissions from specified diseases in these individuals.[2,3] Linked datasets are analysed, managed and stored in the Grampian Data Safe Haven. This ensures that the highest standards of security and governance are adhered to, and to protect patient confidentiality. Previously linked data can also be accessed following necessary approvals.

(Figure 1 here)

(Table 1 here)

(Table 2 here)

Data Resource Use:

The Databank has been used for a number of research related projects - ranging from epidemiological studies within Aberdeen to collaborative work with other units world-wide. These have generated around 200 publications to date. A list of the major publications is available online

(http://www.abdn.ac.uk/iahs/research/obsgynae/amnd/publications.php). Opportunities to study the health of the mother and her baby became obvious from an early date, giving rise to a whole body or programme of research which may be classified as:

1. Effect of events occurring early in pregnancy on the birth of the baby: For example, Bhandari *et al*. using data from AMND between 1976 and 2010 explored the risk of adverse maternal and perinatal outcomes in women with antepartum bleeding of unknown origin (ABUO).[4] The study showed that women with ABUO are at a greater risk of preterm delivery and induced labour compared to women without ABUO. Also, Wijesiriwardana *et al.* assessed pregnancy outcomes in 7627 women with threatened miscarriage at first trimester compared to 31 633 controls and found an increased risk of obstetric complications and interventions in those with threatened miscarriage.[5]

2. How a previous pregnancy affects the subsequent pregnancy and delivery: A study compared the obstetric outcomes in subsequent pregnancies of women who had stillbirths in their first pregnancies compared to women who had live births.[6] Women with previous stillbirths were at higher risk of obstetric and perinatal complications at subsequent pregnancy including preeclampsia, placenta abruption, pre-maturity, induction of labour, instrumental delivery, caesarean delivery, mal-presentation and low birthweight. Another study found that women with a previous miscarriage were at higher risk of obstetric complications in subsequent pregnancies compared to those who had previous livebirths.[7]

3. Following up the mothers to assess their health in later life; Linkage with hospital admissions registers can be used to assess the long term health of mothers following pregnancy related events. Using a subset of AMND data, Wilson et al showed that women with history of gestational hypertension, pre-eclampsia or eclampsia were at higher risk of cardiovascular events in later life.[8]

4. Following up the children: Aberdeen Children of the Nineteen Fifties – Children born between 1950 and 1956 took part in the Aberdeen Child Development Survey when they were at school. Detailed description of the cohort study and how the resource can be accessed have been previously published.[9,10] More information can also be obtained from the website (http://www.abdn.ac.uk/birth-cohorts/1950s/). The study initially aimed to investigate the determinants of learning disabilities among all children attending Aberdeen primary schools in December 1962. Information was collected on childhood height and weight, socio-economic indicators, routine cognitive tests, reading and maths tests scores and teachers' assessment of behaviour. The results from the survey were linked to the birth records of these children stored in the AMND. They were also invited as adults to take part in a questionnaire survey in 1999 and participants in the survey were linked to records of any hospital admissions or death records held centrally in Scotland. More recently, a subgroup of participants (approximately 500) have also been clinically assessed as part of the Generation Scotland study (http://www.generationscotland.org/).

Using record linkage of AMND data with a Support Needs System dataset, a study showed that there was no association between gestational hypertension/pre-eclampsia and additional support needs in children whereas preterm birth and low birthweight were associated with additional support needs.[11] One of the first published studies to show associations between maternal obesity and the risk of cardiovascular morbidity and mortality in the adult offspring was based on AMND data which was linked to the General Register of Deaths, Scotland, and the Scottish Morbidity Record systems for hospital admissions.[2] These exemplify how the database can be used to assess childhood as well as adulthood outcomes in the offspring using record linkage with other registers.

Another 40 year follow-up study was conducted using men and women born between 1948 and 1954 to mothers who had taken part in a survey of diet in late pregnancy. The study showed that mother's diet in pregnancy may affect the blood pressure of the offspring in adult life. [12] A subsequent study, using a similar cohort, was also the first to show that mother's diets during pregnancy are associated with the glucose-insulin metabolism of their offspring in adult life. The authors suggested that dietary high protein and fat in pregnancy may impair the development of the fetal pancreatic beta cells, leading to insulin deficiency in the offspring.[13]

5. Intergenerational research: Due to the availability of intergenerational data, it is also possible to assess inherited factors in relation to obstetric and perinatal outcomes. For example, a study using the data on deliveries in mother-daughter pairs showed that women who were born preterm or have siblings delivered preterm were more likely to deliver their own pregnancies preterm.[14]

In addition, the database has been used to generate clinical standards. In the past, AMND contributed significantly to the development of birthweight standards.[15-18] More recently, data from the AMND have been used to create sex and gestational age specific centile charts for placental weight in nulliparous and multiparous women.[19]

Strengths and weaknesses

The AMND has a number of unique and special features which make it a particularly valuable resource for research purposes. Firstly, Aberdeen City has a relatively stable population and hence births covered in the AMND reflect true population based estimates. A recent tracing exercise using

the Community Health Index (CHI) register in Scotland revealed that only 3.8% of those who gave birth in Aberdeen Maternity Hospital and consequently had a record in the AMND had migrated out of this geographical region which makes it easier to conduct follow-up studies. Also, complete reproductive histories for the women with records in the AMND can be obtained. Moreover, additional data items can be added to the Databank from the original maternity case records for selected cases (this has been done for a previous study[20]) and validity of data can be checked systematically. Furthermore, due to the long duration of data collection, the data allows for the study of secular change, and identification of considerable numbers of intergenerational, sibling and twin pairs for the study of genetic and environmental influences upon reproductive performance and long term health. Also, stringent and consistent criteria are used for the coding of gestation length, birthweight, pregnancy complications, cause of perinatal death and other key variables by trained coding staff. Of additional advantage to studies relating to twins is the fact that zygosity has been determined by DNA testing for the majority of twin pairs from 1968 onwards. Computerisation allows relatively easy identification of complete reproductive histories not only of individual women but also of families. Using this information intergenerational analysis can be performed. Social data is available for most years including occupation for women themselves, husbands or partners, grandfathers, duration of education and lifestyle factors such as smoking.

One of the main weaknesses of the AMND is the issue of missing data in some cases. Particularly, there is no smoking data from 1950 to 1965. Although the AMND covers a relatively stable population, when people do move away there is no record of their subsequent pregnancy related events. Therefore, if a woman has a child in Aberdeen but moves away and has subsequent babies elsewhere she will appear on the database as having one child. Furthermore, Aberdeen City is an affluent area consequently the AMND does not have anyone in the two most deprived clusters of the Carstairs categories of deprivation.[21,22] These may be potential limitations for studies aiming to

assess the impact of these exposures. Also, there is currently a two year backlog of data entry. This issue should be resolved once the NHS converts to a fully electronic record system.

Data Resource Access:

The management of the AMND is overseen by a steering committee consisting of NHS clinicians, data management personnel, academic researchers and lay members. The chairperson of the steering committee acts as the Caldicott guardian. The steering committee is responsible for the preservation of access to the AMND. Requests to access the AMND data must be made through the Databank Steering Committee in order to ensure that the proposed use of the data conforms to accepted scientific standards in terms of methodology, confidentiality and ethics. Access is only available to applicants who, in the opinion of the Committee, are bona fide research workers. They are required to complete and sign the application form which can be downloaded from the AMND webpage (http://www.abdn.ac.uk/iahs/research/obsgynae/amnd/access.php). For enquiries researchers can send emails to amnd@abdn.ac.uk. The AMND is registered with the North of Scotland Research Ethics Service as a research database and thus for research using data from AMND only, formal ethical approval from the ethics committee is no longer mandatory and AMND steering committee approval will suffice.

Once approved, anonymous extracts of the data items requested are provided to researchers and either stored on a secure shared drive or with the University's Data Safe Haven. Data extraction is performed by the Research Application and Data Management Team on behalf of the steering group. Processing and use of data must comply with the requirements of the Data Protection Act. All applicants are required to forward any relevant manuscripts using the supplied data to the Databank Steering Committee prior to submission for publication in order to ensure factual accuracy and

correct interpretation of the material and to ensure appropriate acknowledgement to the Databank. Reference to AMND should be made for the data source on publications and the person that extracted the data should be acknowledged. A format for the acknowledgement is provided on the application form. The Databank Steering Committee, as far as possible, encourage collaborative research with one or more members or designated colleagues within the University of Aberdeen in order to facilitate accurate use and interpretation of the data. Charges for supplying data depend on several factors including origin of the request, whether there has been a previous extraction for the same project and the complexity of the extraction requested. Feedback on charges to be levied is given once the Committee have agreed in principle to the request.

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