The Swedish Medical Birth Register

– A summary of content and quality
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Foreword

One of the principal functions of the Centre for Epidemiology (EpC) at the Swedish National Board of Health and Welfare is, to analyse and report on the national population’s state of health. EpC is responsible for several nationwide registers of medical data. Information on births is reported to the Swedish Medical Birth Register, which is used in many scientific projects. More than 250 scientific studies based on the Medical Birth Register have been published during the past decade. Statistics from register data on mothers, deliveries and newborn infants are also frequently requested. This report summarizes the kinds and the quality of information recorded in the register.

This report is intended primarily for those who use or plan to use information recorded in the Medical Birth Register for various purposes.

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Abstract

This report summarizes the contents of the Swedish Birth Register and analyses its quality. The register is a valuable source of information for reproduction epidemiology. In order to make full use of it, an understanding of its deficiencies is necessary. Some data are missing: Records for a small percentage of all infants (0.5 – 3.9 per cent) are missing completely; for others, the information is incomplete, due for example to missing data from antenatal-care clinics or paediatric wards. The most serious data loss is probably that related to infant diagnoses. Wherever possible, it is useful to supplement information on infant diagnoses with data from the hospital discharge registers of neonatal wards and from the Registry of Congenital Malformations. Single items of information may also be missing to a varying degree. Missing data significantly affect estimates of prevalence but has only a slight effect on risk estimates.

For reproduction epidemiology, studies of the following variables are of particular importance: gestation duration, birth weight, and the incidence of congenital malformations, multiple births and infant survival. (For congenital malformations, the Register of Congenital Malformations is also used.) These variables are fairly reliable. In most cases, adequate data can be obtained with the hierarchical system used for estimates of gestational duration. But for studies of extreme outcomes, such as those involving very low birth weight, caution must be exercised due to the potential for misrepresentation. There are indications that omissions with regard to stillbirths are selective; but only 1–2 per cent of records are missing for most years, which is an acceptable level. Although, the rate of stillbirths are slightly underestimated in the Medical Birth Register. For other characteristics detailed knowledge of data quality and error risks is necessary.

With regard to exposure data, information on smoking in early pregnancy is relatively good (4.2–9.0 per cent missing), while information on maternal drug use is incomplete. Some estimates indicate that the reporting/recording rate for drugs, such as those used for epilepsy and hypertension, is perhaps 60–70 per cent. Since all exposure data are obtained prospectively (i.e. before the outcome of the pregnancy is known), this will have little effect on risk estimates. Lack of data on the exact timing of various exposures can bias risk estimates toward one. Missing data will obviously affect all estimates of prevalence, but will usually have little impact on risk estimates if the lack of information is random.

In order to maintain the register at a reasonably high standard, it is recommended that evaluations be made at regular intervals, and that the effects of the increasing use of computerized medical records be closely monitored.
History

The Swedish Medical Birth Registry was established in 1973 by an act of the Swedish parliament. The purpose of the register is to compile information on ante- and perinatal factors, and their importance for the health of the infant. Even though the basic structure of the register has remained unchanged during the years since 1973, there have been major modifications to content and methods of data collection.

During the first phase (1973–1982), the register was constructed from summarising documents prepared by secretaries at obstetric clinics. These documents were called "Medical Birth Reports" (Medicinskt Födelsemeddelande), and summarized the contents of the medical records on a standard form. Identical medical records and Medical Birth Reports were used throughout Sweden, with the exception of Malmöhus County where a special record form was used and computerized locally. There were some minor differences in the contents of the Malmöhus records and those used in the rest of the country; in the former, for example, the only antenatal diagnoses recorded were those made in hospital care during pregnancy.

The Medical Birth Reports were used primarily for communication between the delivery unit, the antenatal centre, and paediatric health care. It was prepared in multiple copies, one of which was sent to the National Board of Health for computerization. This copy contained only information that was considered relevant to a national register.

In 1976, the register’s content was evaluated, and one result was that the use of natal medical reports was abandoned. Instead, copies of the three medical records of primary interest were to be sent to the National Board of Health for computerization. The objective was to eliminate uncertainty in data transfer to the Medical Birth Registry. The three records of primary interest were: the basic record of antenatal care of the mother, the delivery record, and the record for the paediatric examination of the newborn infant.

The revised procedure went into effect in 1982. At the same time, the content of the register was expanded, and some other changes were also made. One of the changes concerned diseases during pregnancy. Previously, specific diagnoses had been noted with ICD codes; in the new procedure, a number of serious conditions were listed and their presence was indicated in check boxes. Information on eight such conditions was recorded in the register. For certain other categories of information, e.g. administration of analgesics, check boxes were used, instead of codes.

This procedure has been followed since 1982 but from 1994–1995, a copy of an additional record form was requested from antenatal-care centres to supply more information on the care provided.

The content of the register was modified in 1990, 1994 and 1998. Appendix I summarizes the register content and indicates the time periods for which information on each item is available. It should be noted that some information has been derived from other sources, most notably from the
Birth Register maintained by Statistics Sweden and the Cause-of-Death Register kept by the Centre for Epidemiology.

Most of the women (see below) are identified by their unique personal identification numbers (PIN). Every legal resident of Sweden is assigned a PIN, which is used in a wide variety of contexts, including health care, and makes it possible to establish links between different registers. The PIN of a newborn is linked to the Medical Birth Register from The Birth Register at Statistics Sweden. The PIN consists of eight digits for the birth date (year-month-day), followed by three digits that identify the individual and a tenth digit which is a check digit.
Method for the evaluation of register quality


The following summary reviews the results of the most recent evaluation, which also includes some earlier data.

From the 1998 Medical Birth Register, 582 deliveries were selected for the medical record control. This sample included 423 cases that were selected at random from the complete register; 97 were randomly selected among pre-term births, and 62 among deliveries terminating in infant mortality. Copies of the original medical records were requested from the hospitals involved, and were received for 554 deliveries. In six cases, however, the records referred to the wrong delivery (one case), or the documentation was inadequate.

Thus, copies of the medical records were obtained for 548 cases (94 per cent) from the original sample. For some of these, individual documents were missing. Therefore, the review was limited to 513 of the antenatal-care records, 540 delivery records, and 533 paediatric records. The register data for these documents were compared with the medical records. In addition, the information recorded in 1973 to 1998 was analysed.
Results

Missing records

Births may not be recorded in the register when documents relating to delivery are not sent by the delivery hospital to the register. Every year, infants reported to the register are compared with infants reported to the Birth Register at Statistics Sweden. When missing cases are discovered, an effort is made to obtain copies of the medical records from the hospitals involved, but this is not always successful. Consequently, about 1.4 per cent of all infants born in Sweden are not recorded in the register.

Between 1973 and 1998, a total of 2,700,061 infants were born in Sweden, according to Statistics Sweden. During this time, 2,672,423 infants were registered in the Medical Birth Register. Of these, 2,647,988 (98.1 per cent) were recorded in both registers, 37,935 (1.4 per cent) appeared only in the Birth Register at Statistics Sweden, and 24,440 (0.9 per cent) only in the Medical Birth Register. Some, perhaps most, of the last category are included in the 1.4 per cent that are only present in the Statistics Sweden register; but due to PIN-related errors (see below) no linkage was possible.

Analysis of register variables

Mother’s identification number

Every mother of a newborn infant should be identified by her PIN. In 872 cases (0.03 per cent), the PIN was invalid. In 273 cases (0.01 per cent), the last four digits of the PIN were missing (0.01 per cent), and in 15,316 cases (0.57 per cent) they consisted of three zeroes (000) and a check digit indicating an immigrant or refugee who had not yet received a Swedish PIN but may have been listed in the register of Statistics Sweden. A total of 932 women (0.03 per cent) have a “faked” PIN, usually consisting of all 9s, or none at all. These are probably women who have refused to divulge their PINs to the registry.

Date of first visit to antenatal-care clinics

This item of information is available from 1995, but was lacking in nearly 60 per cent of cases during that first year. In the three subsequent years, 1996–1998, the information was available in 94, 93 and 90 per cent of cases, respectively. The most frequent time for an initial visit to an antenatal clinic was after ten full weeks of pregnancy. Roughly 90 per cent have made an initial visit after twelve full weeks. Only a few women make their first visit before the end of week eight. In the medical records sample, the date of the first visit had not been registered in four per cent of cases. Among the cases for which this item was recorded, there was an error frequency of three per cent.

Use of contraceptive pills or IUD

Information on dates for removal of IUDs or terminating the use of contraceptive pills is incomplete. It can be estimated that, for 2.4–3.4 per cent
of all pregnancies that end with a delivery, use of contraceptive pills was not discontinued until after conception. Among these cases, 26 per cent discontinued use during the first month after conception, 51 per cent during the second month, and 23 per cent at a later stage. The percentage of pregnancies among women using IUDs was 0.7–1.3 per cent.

**Mother’s pre-pregnancy weight, weight increase, weight at delivery, and height**

These data have been compiled from 1983 onwards. Pre-pregnancy weight (in effect, weight at first antenatal-care visit) data are available for 70 per cent of the women. For the years 1990–1991, practically no data are available; for the other years, the percentage varies between 73–88 per cent. Information on weight gain during pregnancy is available in about 60 per cent of women, ranging from 29–86 per cent for various years. For technical reasons, the figures are uncertain for the period 1983–1990. Data on weight at delivery are lacking for the years 1990–1993, but are available for 77–89 per cent of women before 1990 and for 33–43 per cent after 1993. Height is known for about 80 per cent of the mothers, and only relatively few values are invalid.

From these data, it is possible to calculate the body mass index (BMI) for about 65 per cent of the women with a reasonable accuracy. (Data are missing for two years; otherwise, the rate varies between 65–85 per cent.)

**Use of tobacco products**

Information on maternal smoking noted at the first antenatal care visit is available since 1983. Information is lacking for 4–9 per cent of women. The percentage of expectant women who reported smoking declined from 31 per cent in 1983 to 13 per cent in 1998. The validity of the smoking information can be evaluated by correlating the mean birthweight of singleton infants with reported maternal smoking.

The mean birthweight of boys born to non-smoking mothers was 3638g. For mothers who smoked less than ten cigarettes per day, the average birthweight of boys was 3465g; and for those who smoked ten or more cigarettes per day, the average birthweight was 3393g. The corresponding figures for girls were 3511, 3336, and 3275g, respectively.

The mean birthweight of infants whose mothers gave no information on smoking in early pregnancy was 3509g for boys and 3393g for girls, indicating that this category included a mixture of smokers and non-smokers. In the medical record sample, about two per cent of the available data on smoking had not been computerized, and in about one per cent the information was misrepresented.

Information on maternal smoking during weeks 30–32 was introduced as a variable in 1990, but was lacking in most cases. There were no such data for 89 per cent of women in 1991, for 67 per cent in 1995, and for 67 per cent in 1998. Information on smoking during late pregnancy and during the three months before pregnancy is incomplete and hardly useful. Where available, it indicates that very few women started smoking during pregnancy, and that the majority of those who smoked three months before reduced their smoking or quit altogether in early pregnancy.
Information on snuff-taking was not collected until 1999. In 2000, 18 per cent of the women provided no information on the use of snuff before or in early pregnancy, and 48 per cent provided no such information for weeks 30–32.

**Family situation**
For the years 1973–1981, the following categories were used: unmarried, married and previously married. Information was lacking in about 10 per cent of women. From 1982 onwards, the categories were changed to: co-habiting, living alone (not available for 1992–1994) and other family situation. For 1982, family status was not known in nearly half of cases, and for 1991–1992 the figure was 13–17 per cent. For most years, about five per cent of these data were lacking.

**Work outside home, occupation**
For this variable, information was lacking for about 25 per cent of the women. Women engaged in some type of formal education were sometimes registered as working, sometimes as not working. Occupation was given in clear text and was often unspecific. In the medical record sample, twelve per cent of stated occupations were not computerized. Accordingly, this information has a low validity.

**Involuntary childlessness**
During the first visit to the antenatal care centre, the woman is asked whether she had tried to conceive without success for an extended period. If so, the number of unsuccessful years is recorded. No involuntary childlessness were stated in 93.6 per cent of cases during the period 1983–1998. There were, however, a number of improbable or impossible stated periods. In addition, there was an obvious lack of information in some cases. Only about 60 per cent of the women who had undergone in vitro fertilisation (IVF) reported a period of involuntary childlessness. Also, information about the specific method used for treatment of childlessness was incomplete or incorrect in some cases.

The study of medical records disclosed some of these discrepancies. For instance, of the nineteen assisted conceptions marked in the register, one had no such information in the record; and five women noted in the medical records were not so labelled in the register. A similar situation existed with regard to ovarian stimulation.

This does not mean that the information is of no use. Most likely, most of the data related to fertility problems lasting 1–19 years are correct and can be used, for example in studies where subfertility may be involved as a confounder. The treatment information is less valid, and better information is needed for detailed follow-up of IVF pregnancies.
Previous pregnancies
The register contains information on the number of previous spontaneous abortions and extra-uterine pregnancies. Among the women in the medical-record sample, there were 103 registered spontaneous abortions. In one of them, there was an extra-uterine pregnancy and not a spontaneous abortion; and in three cases, the recorded number of previous spontaneous abortions was wrong. Six cases (six per cent) of previous spontaneous abortion noted in the medical records had not been entered in the register. There were twelve cases of previous extra-uterine pregnancy recorded in the register; two of these entries were incorrect (both were spontaneous abortions). One case noted in the medical records was not included in the register.

Although the information on previous spontaneous abortion is not perfect, it is reasonably reliable.

According to the register, 21 of the women in the sample had experienced a previous stillbirth. But for 13 of these, the information was incorrect; twelve actually involved live births. In two cases, the medical records contained information on previous stillbirths that was not entered in the register. In order to identify pregnancies following a stillbirth, a more reliable method is to use register information on previous births. The same is true of information on the deaths of newborn infants: It was incorrect for four stated cases of death during the first week of life; two such cases were not recorded at all. Only three recorded cases of death after the first week were noted in the register, and two such cases were not recorded.

The register contained information on 236 previous live births. In three cases, the number of live births per woman was incorrect; and there were 21 additional previous live births (eight per cent) that had not been recorded in the register.

Parity
Related to this is the problem of parity. There are two sources for parity: One is based on the number of reported previous stillbirths and live births (+1), the other on data from Statistics Sweden. When the two sources are compared, major discrepancies are found. These data can also be compared with the number of previously registered infants in the Medical Birth Register (estimated parity).

Analysis shows that for singleton births, the parity data from Statistics Sweden agrees with the estimated parity in 98 per cent of cases. For women born in Sweden, the parity information based on reported previous births in the Medical Birth Register agrees with the estimated parity in 91 per cent of cases; but for the period from 1982–1989, the level of agreement is only 85–89 per cent, and for 1990 only 54 per cent. For women not born in Sweden, the difference between the parity data from Statistics Sweden and the estimated parity is larger; the level of agreement is only 91 per cent. Agreement with the Medical Birth Register, is also 91 per cent (similar to the level for women born in Sweden).

Thus, the best parity estimate is that obtained from Statistics Sweden. But especially for immigrant women, some errors exist due to the fact that registration of births which take place outside Sweden is incomplete.
Parity information regarding multiple births is poor, whether derived from Statistics Sweden or the Medical Birth Register. In principle, the first twin to be born should have a parity equal to the number of previous infants born, plus one. The second twin should have parity equal to the number of previous infants born, plus two. This principle was not followed in the Medical Birth Register for the years 1973–1997, when both twins were assigned the same parity. There is a problem with parity data from Statistics Sweden, since it is not known which twin is born first. As a result, parity is switched back-and-forth between the twins, although the annual variation is great; the problem affected 2 per cent of cases in 1984, 64 per cent in 1987, and on average around 13 per cent. For the period from 1992–1997, Statistics Sweden used a special parity designation. If a woman had a twin delivery in her first birth, the first twin was assigned a parity of two, the second a parity of three.

When parity data from Statistics Sweden or from the Medical Birth Register is compared with estimated parity (see above), there is agreement for only some fifty per cent of multiple births. Great care is required when parity information for multiple births is used: the best solution is to base parity on the number of previous births, plus one.

**Diagnoses before and during pregnancy**

For the years 1973–1982, diagnoses during pregnancy could be noted in the form of ICD codes, in one county (Malmöhus) restricted to hospitalisations. After 1982, this system was replaced with check boxes for certain diagnoses regarded as especially important. In these boxes one could mark differently previous diseases from ongoing diseases.

The information provided is based on interviews performed by midwives. The check-box method has been shown to be rather poor. The recorded incidence of diseases with a known prevalence in the general population is often absurd. For instance, one would expect that about 350 women annually would be noted as having pre-existing type I diabetes; but according to the marked check boxes, the number varied between 866 and 1479 during 1973–1989, and between 3095 and 7485 during 1991–1998.

Another example: maternal epilepsy should have occurred in approximately 350 cases per year. The recorded numbers varied between 107 and 229 for the period 1973–1989, between 275 and 376 during 1991–1996, and 95 in both 1997 and 1998. The middle period thus appears to reflect a reasonable rate.

For the medical-record sample, it appears that, check-box information is largely missing for 1998. Of sixty instances of repeated urinary-tract infections, only nine were recorded in the register. Not one of the six cases of chronic kidney disease, seven of type I diabetes, two of epilepsy, one of ulcerous colitis/Crohn’s disease, one of SLE, and four of chronic hypertension was recorded in the register. Of 21 cases of pulmonary disease, only six were recorded.
Number of visits to antenatal care centre
This item was introduced in 1994, but it was not until 1996 that the majority of the records included such information. Even then, however, it was missing, or coded as 99 for “unknown”, in eleven per cent of cases.

Prenatal diagnosis
For the years 1995–1998, a mark for chorion villi sampling (CVS) or amniocentesis could be made, and date when the procedure was performed could be given, along with the outcome (normal or abnormal). During those years, CVS was noted for 868 patients; the check box was marked for 86 per cent of these, a date was noted for 70 per cent, and the outcome indicated for 40 per cent. Amniocentesis was noted for 5297 patients; the check box was marked for 96 per cent of these, for 82 per cent a date was noted, and for 81 per cent an outcome.

In the medical-record study, eleven cases with amniocentesis were marked in check boxes, and an additional ten cases could be identified. Thus, only about half of all cases were recorded.

The location of this item in the medical-record form was changed in 1999, in order to obtain more accurate records. Compared with 1998–1999, this has resulted in an approximate doubling of the recorded number of CVS and amniocentesis during the years 2000–2001. It is possible that nearly all cases are now recorded.

Date of admission to delivery unit
In the majority of cases, this date has been recorded. About 88.5 per cent of the women were admitted on the day of delivery or the day before, and about eight per cent within two weeks prior to delivery. Some dates indicate admission more than seven weeks prior to delivery, or after delivery; the majority of these notations are probably wrong, but together they only represent 1.2 per cent of the total.

In the medical-record study, an admission date was noted in 539 cases; for nine of these, minor differences from the record were observed.

Number of foetal membranes
This variable was introduced in 1994 in order to identify multiple births with two or four membranes. The information is missing from the register in most cases, and a significant proportion has impossible values. The information cannot be used.

Foetal presentation
For the period 1973–1981, information on foetal presentation was derived from the last decimal in the ICD delivery code. From 1982 onwards, this information is instead based on check boxes. The number of unknown presentations amounted to 5–8 per cent during 1973–1981, increased to nearly half in 1982, then declined to about 25 per cent during 1983–1986. For the period from 1988–1989, nearly all information is missing; after 1992, some 3–10 per cent is missing. Except for years 1988–1989, the number of various
non-normal presentations is fairly stable, and it is likely that the majority of unknown presentations were, in fact, normal head presentations. Even if there is some uncertainty, it seems likely that information on, for example, breech presentation can be used for analysis. In the medical-record analysis, information on presentation was available for 478 cases in the register. In one case, the register information did not agree with the medical-record information; and in 37 cases (seven per cent) the medical records contained information which had not been registered, including 35 normal head presentations.

**Placental weight**
Information on placental weight is available only for years 1982–1989. For years 1983–1989, information is missing for 21 per cent of single births and 22 per cent of multiple births. The mode value for placental weight was 500–599g for single births and 1000–1099g for multiple births, i.e. the sum of the two placentas.

**Number of umbilical vessels**
This information, as well, is available only for 1982–1989. For years 1983–1989, valid values (2 or 3) are available for 97 per cent of the 93 per cent of the cases for which information of any kind was recorded.

**Mode of delivery**
During the entire register period, the delivery method has been noted as either spontaneous vaginal, forceps, vacuum extraction, or caesarean section. For the period 1973–1982, this categorization was based on the operation codes recorded. Starting in 1982, delivery method was marked in a check box, but was supplemented with possible operation codes. For the period 1983–1989, a special check box was used for marking elective versus emergency section. During this period, 82.7 per cent of all deliveries were non-instrumental vaginal, 0.3 per cent were forceps, and 5.7 per cent vacuum extractions. Caesarean sections accounted for 11.3 percent of the total; 4.2 per cent were marked as elective and 4.7 per cent as emergency, while the remaining 2.4 per cent were not specified.

In order to better distinguish between elective and emergency sections, a new method was introduced in 1989 and remained in effect until 1998. During this period, caesarean sections which began a delivery were classified as elective; those which ended a delivery that had begun without a section were classified as emergency. Of 711,575 deliveries, 5.3 per cent were recorded as starting with a section and 10.5 per cent as ending with a section. The total rate of caesarean sections was 11.6 per cent, which in this case would mean that 46 per cent were elective. However, a review of the data indicated that, as expected, a delivery recorded as elective may have started with an emergency section (e.g. after heavy bleeding before the start of the delivery process). A comparison was therefore made between data in the Medical Birth Register and data on the same patients in a local data base (Perinatal Revision Syd). For preterm deliveries (<37 completed weeks), only 22 per cent of deliveries noted in the Medical Birth Register as having started with a section (and therefore regarded as elective) were actually
elective, while the corresponding figure for term pregnancies was 87 per cent.

The review of 1998 medical records identified 80 preterm deliveries, of which 47 were recorded as having started with a section and were therefore regarded as elective. Only seven of those 47 (15 per cent) were actually elective, according to the medical records, and 34 (72 per cent) were emergency; for the remaining six cases (13 per cent), it could not be determined whether the section was emergency or elective. Of 52 caesarean sections at term deliveries, 20 of which were labelled elective, 15 (75 per cent) were elective, four were emergency, and one undecided. These data thus confirm that the register information is reasonably adequate at term deliveries, but that the frequency of elective sections at preterm deliveries is grossly overestimated. With a beginning during 1999, a further check-box has been introduced with which elective/emergency section can be specified.

The review of the medical records also revealed some miscoding, and that some information in the records had not been transferred to the register. Thus, nine per cent of non-instrument vaginal deliveries and two per cent of caesarean sections had not been recorded.

**Analgesia and anaesthesia**

Until 1983, information on analgesia/anaesthesia was derived from recorded codes; after 1983, check boxes were used. A substantial proportion of cases (about 15–20 per cent) are completely lacking in information, which makes it impossible to know whether the woman had received no analgesia or if it was not recorded. Starting in 1982, a check box for "no pharmacological analgesic given" was introduced. This has been marked in about 1 per cent of all cases (with a significant decrease during the last few years), and has little effect on the number of cases lacking information.

The medical-record study found a few non-recorded data and frequent miscoding of nitrogen dioxide as pethidine- probably due to an error in a storage program. It was also noted that, in some cases, general anaesthesia in connection with caesarean section was not recorded, the record indicating instead that the section was performed without analgesia or anaesthesia.

**Mother’s discharge date**

The mother’s discharge date is lacking in very few cases: 0.006 per cent for years 1973–1981, 0.5 per cent for 1982–1989, and 1 per cent for 1990–1998. For a few women, discharge predates the delivery date: 0.1, 1.0 and 0.9 per cent, respectively, for the three periods noted above. This is probably explained in part by misrepresentation of dates, and partly by the inclusion of dates from hospitalizations during pregnancy. Some very long hospitalization periods are probably explained by misrepresentation of dates.

In the medical-record sample, dates included in the record but not in the register occurred in only 0.4 per cent of cases. In one case the date was wrong (September instead of July), and in four cases minor discrepancies were observed.
Hospital code
For the period from 1973–1998, the register contains 100 valid hospital codes for 2,628,832 deliveries, and 383 invalid codes for 1799 deliveries (including 662 of which lack hospital codes altogether). A comparison was made between the Medical Birth Register and a local register (Perinatal Revision Syd) in order to check the correctness of the codes. The local register contains obstetric and neonatal data from eleven hospitals in southern Sweden. Of 62,604 compared records, errors in hospital codes were found in 0.9 per cent. Incorrect hospital codes can sometimes be explained by simple misinterpretation (e.g. code 30001 has been read as 50001); but there are also some systematic errors which are probably due to data-storage procedures.

Type of mother’s discharge
For the period 1973–1981, this information is nearly always available; except for 1973, it is lacking in less than 1 per 1,000 cases. For 1982–1989, this information is completely lacking, and the same applies to a majority of the 1990 records (65 per cent). In the following years, the percentage of missing information decreases from 23 per cent in 1991 to three per cent in 1998.

In the medical-record study, a few cases (0.4 per cent) with information in the record but not in the register were found. Also, one error was found: A woman who died during delivery was coded as having been discharged to her home. There is another problem, as well. When a woman is moved to a patient hotel after delivery, it may be coded as 1 for ”home” or 2 for ”other institution”; this varies not only between hospitals, but also within hospitals.

Child’s identification number
This number is linked from Statistics Sweden to the Medical Birth Register, and is based on the mother’s identification number and the infant’s date of birth. In spite of this, there have been some errors in the identification numbers of infants, most notably in 1984. Apparently, the explanation is that only the last four digits have been transferred and, if the date of birth is wrong, an incorrect identification number will result. For most years, about 2–3 per 1000 infants have an invalid identification number, and slightly more lack complete identification numbers. Very few also lack the first eight digits, corresponding to the date of birth.

Time of day for delivery
The time of day is recorded for the majority of deliveries. For 1973, this information is lacking for 0.8 per cent of vaginally delivered infants, and for 0.9 per cent of infants delivered by caesarean section. For the period 1974–1981, the information is lacking for only 0.01–0.11 per cent of vaginally delivered infants and 0.02–0.20 per cent of infants delivered by caesarean section. For the period 1982–1998, the corresponding figures are 0.31–1.07 per cent and 0.64–2.01 per cent. Generally speaking, this information is lacking twice as often for infants delivered by caesarean section as for infants delivered vaginally. For a few cases (189), the time of the day is invalid.

In the medical-record study, the time of day noted in the record was not entered in the register in 0.4 per cent of cases. Of 530 times recorded, ten were incorrect and six were incomplete (hour or minutes lacking).
Multiple births
The information on the number of infants in the birth is obtained from the infant record (FV2) for the entire period and, for 1984–1998, also from the delivery record (FV1). There are forty women for whom the number of infants in the multiple birth exceeds five (35 of them are recorded as nine).
This information can be supplemented with a maternal diagnosis of twin delivery, and with an infant diagnosis of being a twin.

Twins
If all infants recorded as twins are counted, the total is 58,304. This includes 28,451 whole pairs, five sets of triplets which have been marked as twins, 24 pairs with one of the twins in duplicate, and 17 sets with both twins in duplicate.
Of the infants recorded as twins but whose co-twin is not recorded, 444 are most likely twins (they are recorded as twins in FV2). In 313 cases, the only indication that the infant is a twin is a neonatal infant diagnosis, and in 415 cases the only indication is a maternal diagnosis. In eight cases, both maternal and infant diagnoses indicate twins; In nineteen cases, the twin information is recorded in FV1 but not in FV2, and in three of these cases it is supported with a maternal diagnosis.
One explanation to the discrepancy between diagnoses and number of infants in a birth could be twin deliveries where one of the twins dies before legally becoming an infant.
The information on twins in FV1 was introduced in 1982. During the period from 1983–1998, a total of 37,860 twins were born, as noted in FV1 or FV2. Only thirteen were recorded only in FV1, and 1,849 (37 per cent) only in FV2. Of the thirteen recorded only in FV1, there were three whole pairs; they were recorded as multiple births but not twins in FV2, although they were definitely twins. The remaining seven infants could have been "single" twins or singletons erroneously classified as twins.
Despite some uncertainties and errors, the information on twins is largely correct.

Triplets
A total of 1583 infants have been recorded as triplets. Of these, 515 are presented as complete triplets. In thirteen cases there are only two infants, and in twelve cases only one in the register. No triplets are recorded for 1983 (some were born, but never recorded).

Higher order multiple birth
There are a total of 110 infants recorded as quadruplets- 26 in complete sets, one set with only two infants, and one set with only one infant.
There are only two sets of quintuplets, both born in 1982.
Live birth and stillbirth
Stillbirths can be identified in two ways: a mark in a check box or from the infant’s personal identification number.

There is a slight discrepancy between stillbirths in the Medical Birth Register and in the register of Statistics Sweden. The most frequent difference is for stillbirths born before 28 full weeks of pregnancy. According to Swedish law, such births are to be regarded as late abortions, not stillbirths, and should not be included in statistics on delivered infants. In some cases, such a foetus has been recorded in both registers, in other cases not in that of Statistics Sweden.

Of the infants recorded as live-born in the Medical Birth Register, 0.2 per cent are not included in the Statistics Sweden data. The same is true for 2.6 per cent of stillbirths.

There are 18 infants marked as stillbirths in the Medical Birth Registry but with a personal identification number indicating live birth – all 18 are wrongly marked in the registry due to a misrepresentation (5 in 1986, 8 in 1990, 5 in 1991).

In the medical-record study, the infant’s life status was correctly recorded in all instances.

Infant sex
The sex of the newborn is noted in the paediatric record, and is also shown by the personal identification number. Among the more than two million infants born, sex information is missing for 200 of those with an identification number (130 boys, 70 girls), and 164 infants had no identification number. For 0.05 per cent of the infants with identification numbers, the sex noted in the paediatric record does not agree with that shown by the identification number. There were no errors with regard to infant sex in the medical record study.

Duration of pregnancy
Determination of pregnancy duration will be discussed more thoroughly later on. Here, it may be noted that duration is based partly on the information in the paediatric record. In the medical-record study, there were 542 instances for which gestational duration was recorded in the register. Four of those records were found to contain errors when compared with the information in the medical record: Values were listed as 93 instead of 39, 52 instead of 25, 40 instead of 41 and 39 instead of 38. Thus, two of the values were clearly invalid, while two involved relatively slight changes in pregnancy duration. In three cases (0.6 per cent), there was information in the medical record that had not been recorded in the register.

The number of days following completed weeks has been recorded in 457 cases. In fourteen of these, the medical record lacks this information: but in the register it is given as three, which results in a skewed distribution of the additional days.
Birth weight
Information on birth weight is lacking for 0.32 per cent of all infants, the rate varying between 0.04 and 1.95 per cent (1994). Some absurd values are given, e.g., less than 300g; but the majority of weights are plausible.

In the medical-record study, birth weight had been registered in 539 cases; one of the weights was incorrect (2345g instead of 2645 g). In two instances, the records showed a weight that was not recorded in the register (0.6 per cent).

Body length
Information is lacking for 0.22–0.50 per cent of infants born during the period 1973–1981, and 1.01–2.58 per cent for 1982–1998. Less than one per 1,000 had a stated length under 33 cm, and less than 0.5 per cent over 55cm.

In the medical-record study, body length was recorded in the register in 472 cases; an additional six cases (1 per cent) had a body length stated in the medical record without it being recorded.

Head circumference
For the years 1973–1989, the percentage of infants for which there was no information on head circumference varies between 1.0–2.3 per cent, between 3.5–3.9 per cent for 1990–1993, and between 6.0–6.7 per cent for 1994–1998. There is a small number of impossible values: about one in 1,000 has a stated head circumference of less than 24 cm, and equally many over 44 cm.

In the medical-record study, a head circumference was stated in the register for 442 infants; for three infants (0.7 per cent) there was a head circumference stated in the record that had not been recorded in the register.

Apgar score
An Apgar score can be stated at one minute, five minutes, and ten minutes. A total of 37,785 infants lack an Apgar score at one minute. For 32,509 of these (86 per cent), there is no score at all or an invalid value (n=3) at five minutes. An Apgar score at ten minutes is missing for 93 per cent of those that had no score at five minutes.

When Apgar at one minute is filled in, Apgar at five minutes is sometimes missing. If the Apgar score at one minute is below 9, there is no score at five minutes in 1.4–2.2 per cent of cases, at Apgar 9 5.5 per cent are missing, and at Apgar 10 25 per cent are missing. It is usually safe to assume that if there is no Apgar score at five minutes, it is probably at least 9 if the score at one minute was 9 or 10.

There are a number of Apgar score values which are valid but incorrect, usually because of an recording error in the register. A common error is that the sequence 101010 is entered as 01010, which is read as Apgar 1=1, Apgar 5=1, Apgar 10=0.

In the medical-record study, Apgar scores were recorded in the register for 518 infants. For an additional six infants (one per cent), there was an Apgar score in the record which had not been stored; two of them had scores of 00 00 00.
In six cases, there were errors in the recording of the scores:

01 00 instead of 09 10
09 10 01. . . 09 10 10
01 01 00. . . 09 10 10
09 01 01. . . 09 10 10
09 10 01. . . 09 10 10
07 07 07. . . 07 06 07

Recording was incomplete in an additional five cases, with data missing when Apgar scores were stored as 00.

Discharge of the infant

Information on discharge of the infant is lacking for 0.6–1.1 per cent of cases during 1973–1981, for 9.2–13.2 per cent during 1983–1997, and for 47.4 per cent in 1998. The high frequency in 1998 is corroborated by the medical-record study: 226 infants were listed as discharged in the register; and for an additional 204 (47 per cent), there was information in the record which had not been registered (47 per cent). Ten of these 204 had not been discharged to their homes.

From 1990 onwards, about 100 infants each year are recorded as "not discharged".

Infant’s date of discharge

For the period 1973–1981, only a few dozen infants each year had a discharge date before the date of delivery (due to recording errors), and for only few was the date of discharge lacking or incomplete. From 1982 onwards, 2–6 per cent of all infants lacked a date of discharge; and for some (as many as 1092, in 1990) the date was incomplete.

Infant’s date of death

The date of death may appear in the paediatric record and can also be linked from the Cause-of Death-Register (which necessitates a correct identification number for the infant). For 985 infants, a date of death was recorded in the paediatric record (981 of them died during the first week of life), but no date of death had been linked due to incomplete identification numbers.

There are an additional 256 infants with a date of death in the paediatric record (228 died during the first week) but not in the Cause-of-Death Register. Of these, 205 are singleton births, 51 (20 per cent) are twins. The latter is partly explained by the fact that, in half the cases of live-born, like-sexed twins, there was no established procedure for distributing identification numbers among them. Therefore, the dead twin (according to the paediatric record) sometimes received the identification number of the living twin and vice versa.

In spite of this, there are 206 infants (205 singletons, 26 twins) for which there is no date of death linked from Statistics Sweden, but a date of death given in the paediatric record. For five of these cases, only, the explanation is that the identification number in the Medical Birth Register is incorrect.
The date of death in the paediatric record is often not recorded in the register. In the medical-record study, this applied to fourteen of 51 dead infants. In most cases, the date of death had not been completed on the FV2 form. In one case, the infant had been selected for study because it had a date of death according to Statistics Sweden, but there was nothing in the medical record to indicate that it had died. It had been referred to a regional clinic and had probably died there without that fact being noted in the medical records of the delivery hospital.

Time of death
When there is a date of death on the paediatric form, a time of death is given in 96 per cent of cases. Missing information on time of death begins in 1989 (one case), and then appears the following years.

In the medical-record study, time of death is recorded in the register for thirteen infants; but in the medical records, time of death is noted for an additional 32 infants (71 per cent). One of the times was entered incorrectly in the register (18.55 hours instead of 15.55). The high percentage of missing information is due to failure to enter it on the FV2 form.

Autopsy
When a date of death was recorded on the basis of FV2, information on autopsies was missing in 23 per cent of cases. An autopsy was marked in 65 per cent of cases, and no autopsy in 13 per cent.

In the medical-record sample, the autopsy information in the register had been completed in 28 cases, but incorrectly in one of these (autopsy marked, but medical record states no autopsy). In a further 7 cases (20 per cent), information was available in the record, in 4 of them autopsy had been performed.

Year of mother’s immigration
This information has been linked for infants born up to 1993. The year of immigration is later than the year of delivery for some twelve per cent of deliveries by immigrant women in 1973, gradually decreasing to 0.2 per cent in 1989, and none after 1989. The explanation is probably that these women have first immigrated, then emigrated, then immigrated once again; what has been linked is the year of the last immigration.

Pregnancy duration
In order to estimate pregnancy duration, a number of variables are used:

- date of last menstrual period (LMP)
- estimated day of delivery (from LMP, possibly modified from clinical investigations)
- corrected estimated day of delivery (from second-trimester ultrasound)
- pregnancy duration as stated in paediatric record
All dates are sensitive to mis-representation, and pregnancy duration estimates may therefore be incorrect. The paediatric estimate (in completed weeks) may also be incorrect; a mistake in one digit may cause a large error.

To get the "best possible" estimate of pregnancy duration, the following hierarchic rules are applied (but the basic data listed above are kept in the register):

1. Pregnancy duration from corrected estimated day of delivery is supported by information in the paediatric record and is then kept. For 1998, this was true for 81.8 per cent of pregnancies.
2. Pregnancy duration from estimated day of delivery is supported by information in the paediatric record and is then kept; true for 8.0 per cent (usually because corrected dates are lacking).
3. The only available information is the paediatric estimate which is then kept; true for 0.65 per cent.
4. Pregnancy duration estimated from LMP date is supported by information in the paediatric record and is then kept; true for 7.5 per cent.
5. Pregnancy duration from corrected estimated date of delivery is supported by pregnancy duration from estimated date of delivery; the former is kept; true for 0.9 per cent.
6. Pregnancy duration from corrected estimated date of delivery is supported by pregnancy duration from LMP; the former is kept; true for 0.1 per cent.
7. Pregnancy duration from corrected estimated date of delivery is the only available information and is kept; true for 0.1 per cent.
8. Pregnancy duration from estimated date of delivery is the only available information and is kept; true for 0.01 per cent.
9. Pregnancy duration estimated from LMP is the only available information and is kept; true for 0.02 per cent.
10. Pregnancy duration from estimated date of delivery and from LMP agree; the former is kept; true for 0.02 per cent.
11. If information on infant sex or birth weight is missing, if it is a multiple birth, or a delivery of a severely malformed infant, an estimate of pregnancy duration is made according to the following hierarchy:
   - estimated from corrected expected date of delivery
   - estimated from expected date of delivery
   - estimated from LMP date
   - paediatric record information

This is true for 0.05 per cent of cases.
12. In all cases where disparate information exists (and none of the above-listed combinations are fulfilled), the estimated pregnancy duration which gives the smallest deviation of birth weight from the normal birth weight/pregnancy duration distribution is kept; true for 0.8 per cent.

Thus, in the majority of cases (97 per cent) pregnancy duration is based on the agreement between a calculated pregnancy duration with that stated on the paediatric record. Among the remaining cases, rather large discrepancies can be found (>5 weeks).

In studies of extreme pregnancy duration (both very short and very long), a dilution will occur with some incorrectly recorded cases. A review of each case with regard to birthweight, body length, head circumference and maternal and infant diagnoses can usually identify deviant cases.

**Maternal delivery diagnoses**

Diagnoses are recorded as ICD codes; mistakes in coding and in representation during computerization occur. There is a tendency to use unspecific codes, even when a specification is possible. One example from the medical-record study is of a woman who was diagnosed for unspecified abruptio placentae (O459), in spite of the fact that it was clear from the record that the problem was actually a coagulation anomaly (O450).

In 1980 (ICD8), a total of 798 different delivery diagnostic codes were registered but ten or more cases existed for 295 codes and these represented 98.7 per cent of all given diagnoses. The majority of the remaining codes are the results of recording errors.

The corresponding figures for 1990 (ICD9) were 1446 total codes, 238 of them with ten or more cases representing 98.0 per cent of all codes. For 1998 (ICD10), there were 1977 total codes, 349 with ten or more cases representing 98.2 per cent of all codes.

Thus, the majority of diagnostic codes recorded at delivery were reasonable.

Based on the medical-record study, it appears that 43 of 1264 diagnoses were incorrect, doubtful, or could have been replaced by a more suitable diagnosis (3.5 per cent). One example is that of a woman with pre-existing diabetes who was assigned code E10.9 instead of O24.0 (the first code also means diabetes, but the O-code should be used at pregnancy).

It is further apparent that some serious diagnoses were not included. One such example involved an ultrasound exam which had demonstrated severe foetal growth retardation, but for which code O36.5 was not assigned. One explanation could be that, up until 1998, a maximum of only four different delivery diagnoses could be coded; since 1999, the maximum has been twelve.
Operations and other procedures at delivery
A specific code list was used until 1987, and was then replaced with a new list. The same phenomenon as with ICD codes is seen; i.e. invalid codes are used. Such codes represented 3.5 per cent of all codes recorded in 1991, and 1.8 per cent in 1998.

Infant diagnoses
The main problem with infant diagnoses is when there is a nearly complete lack of them. This was relatively rare during the period from 1973–1981, when there were usually less than 100 such cases annually (a rate of less than 1/1000). For 1982–1989, the frequency increased to 2–3 per cent; after 1990 the rate increased further to about ten per cent, and in 1998 to the level of fifteen per cent. To a large extent, these cases probably represent infants that were transferred to neonatal units, and there was no feedback of discharge diagnoses when they were reported to the register. However, this phenomenon is unevenly distributed among hospitals. For 1998, less than ten per cent of records in the majority of maternity hospitals lack infant diagnoses; but some hospitals lack such information for up to 79 per cent of cases, which cannot be explained by neonatal transfers. Many of these hospitals use the computer program, Obstetrix, to maintain delivery records. The proportion of cases with missing information among all hospitals using that program is 22.1 per cent; for all other hospitals, the rate is 10.7 per cent.

In 1980 (ICD8), a total of 798 different codes were used, 585 of them in less than ten cases (1.3 per cent of all diagnoses). The corresponding figures for 1990 (ICD9) are 1300 diagnoses, of which 1118 were used less than ten times (six per cent of the total). For 1998 (ICD10), there are 1148 diagnoses, 997 used less than ten times (3.6 per cent of the total).

In the medical-record study, there was no infant diagnosis in the register for 64 cases for which diagnoses were noted in the records; 36 of these had the diagnosis "normal infant". Diagnoses of malformations, many of them serious, were recorded in the medical records for 29 infants who lacked such a diagnosis in the register.

Recording maternal drug use
As noted above, maternal drug use during pregnancy is recorded at the first antenatal care visit (i.e. for drugs used prior to that visit); drugs prescribed during the antenatal care are also recorded.

The first category basically represents drug use during the first trimester, which is of interest for studies of congenital malformations. The information is derived from the woman reporting the drug and the midwife recording it. More than a quarter of all women report some drug use during this period. Exactly how much is omitted is not known; but some estimates indicate that the reporting/recording rate for "serious" drugs, such as those used for epilepsy and hypertension, is perhaps 60–70 per cent. A comparison with prescriptions in one county indicates that the same is true for antibiotics. For drugs regarded as less "serious", such as minor analgesics, it is likely that the reporting/recording is lower; but no definite figures are available.
For the second category – drug use recorded during antenatal care – it should be noted that this refers mainly to drugs prescribed by antenatal care services. Records of drugs obtained from other sources are probably inadequate.
Medical Birth Register: Overview and Discussion

As with all large registers, there are errors in the data recorded and some data is missing from the Medical Birth Register.

A relatively small proportion of births are not registered. There are indications that omissions with regard to stillbirths are selective; but only 1–2 per cent of records are missing for most years, which is an acceptable level. In determining the rate of stillbirths, for example, it must be kept in mind that they are slightly underestimated in the Medical Birth Register. In recent years, however, there is a trend toward an increasing percentage of missing cases (0.9–3.9 per cent), perhaps related to use of computer programs in preparing medical records. If very strict routines are not applied, there seems to be a risk that some cases are lost for registration.

In order to be included in the Medical Birth Register, a delivery record (FV1) must be present. But other documents (records either from antenatal-care clinics or from the paediatric examination of the infant) may be missing. There is reason to suspect that use of computerized medical records at delivery but paper-based records from antenatal clinics may hinder complete registration. As a growing proportion of hospitals are computerizing their medical records, solutions for such problems have a high priority.

Even when all documents have been submitted to the register, individual items may be missing. One example is information on smoking, which is lacking in about 4–9 per cent of cases. Either the data have never been entered in the medical records, or it has not been entered in the register. The medical-record study indicates that this occurred for only a few per cent of most items. Part of the explanation may be that unclear copies were sent to the National Board of Health and Welfare. For some items, such a large proportion is missing that analysis appears to be impossible. One example is smoking in late pregnancy (up until 1998), for which too much data have been lost, probably due to poor design of the record form. One way in which data may become unavailable to the register is through the improper use of medical-record forms – for instance, if an epicrisis has been obtained from the neonatal ward but the discharge diagnoses have not been transferred to the form sent to data registration (FV2).

The most serious data loss is probably that related to infant diagnoses, particularly for infants who have been transferred to neonatal wards. It is possible to supplement such data with discharge diagnoses from neonatal wards, which are recorded in the Hospital Discharge Register. For congenital malformations, supplementary data can also be obtained from the Register of Congenital Malformations. Using these registers, it is possible to increase the ascertainment of congenital malformations to a reasonable level. Such a procedure is recommended for final epidemiological analyses of congenital malformations.
Missing data will obviously affect all estimates of prevalence, but will usually have little impact on risk estimates if the lack of information is random.

For studies in reproductive epidemiology, pregnancy duration and birth weight are often key variables. In most cases, adequate data can be obtained with the hierarchical system used for estimates of gestational duration. At the extremes of the distribution, however, extra care must be observed in order to weed out faulty data which may be present in a considerable proportion of the cases. The same is true for birth weight. – Those data are fairly reliable; but for very low and very high birth weights, an admixture of normal birth weights will occur and a review of individual records is recommended.

For other characteristics, as well, detailed knowledge of data quality and error risks is necessary. For example, normal infants may receive very low Apgar scores due to recording errors; but it is usually possible to identify and correct such errors.

The association between drug use and congenital malformations provides a concrete example of how register errors may affect conclusions.

The following problems will exist:

1. Drugs are taken but not reported/recorded. This will only little affect risk estimates.

2. Drugs may be reported but not taken. This is rather unlikely but may occur if, for example, a woman reports using folic acid but in fact did not do so.

3. Drugs are reported as taken during the first trimester, but were really taken before or after.

4. Only single tablets of the drug are taken, a situation which may not be possible to distinguish from situations involving regular use of high doses.

5. All infants with congenital malformations are not identified. This will only have a limited effect on risk estimates.

Items 2–4 all bias risk estimates toward a value of one; they may therefore conceal a drug effect, but cannot “create” one.

The biasing of risk estimates toward a value of one thus reduces the potential for identifying an existing risk. It should however be noted that large numbers can be obtained using the register which results in an increased statistical power; this offsets and usually outweighs that bias.
Summary of Medical Birth Register Contents

A) Identification of patient
maternal PIN, infant PIN, maternal place of residence (parish) at delivery, delivery hospital, antenatal-care centre (1998-).

B) Social factors


C) Maternal history
previous pregnancies: induced abortions (-1981), spontaneous abortions, stillbirths, live births, perinatally dead infants, later dead infants.
involuntary childlessness, no. of years (1982-)
method for assisted conception (1994-)
use of contraceptive pills or IUD before pregnancy (1982-)
previous CS, inc. year (1999-)

D) Pregnancy
LMP date
expected date of delivery according to LMP and sonography (1982-)
CVS or amniocentesis, inc. date and outcome (1994-)
selected diseases at first visit to antenatal clinic
drugs used during pregnancy (1995-)
number of antenatal visits (1998-)
date of first antenatal visit (1998-)
E) Delivery
- date of admission to delivery unit
- pregnancy duration (weeks, days)
- presentation of infant
- delivery diagnoses
- operations at delivery: CS, forceps, vacuum extraction, other
- analgesia, anaesthesia with specification
- induction of delivery (1998-)
- placental weight (-1982)
- number of umbilical arteries (-1982)
- ruptures (1999-)
- perineotomia (1999-)

F) Infant
- date and time of birth
- stillborn/live-born
- date of death, underlying cause of death
- sex
- birth weight
- birth length
- head circumference
- multiple birth, inc. number
- Apgar score at 1, 5, 10 minutes
- infant diagnoses
- operations and other treatments of infant
The general purpose of the Centre for Epidemiology is to describe, analyse and report on the development and distribution of health, illness and social problems and their determinants among various subgroups of the Swedish population, as well as the utilization of health and social services. The primary responsibilities of the Centre for Epidemiology are to: compile and maintain epidemiological registers of high quality; develop and adapt classification systems; co-ordinate work on the development of national terminology within the areas of health and social services; produce national reports on public health and social conditions; initiate and conduct research and development; and co-ordinate statistics within the areas of health and social services.