Socialstyrelsen

Item number: 2021-9-7547 Version 1
Publication date 14/09/2021

Department of Registers and Statistics
Henny Rydberg, Helena Månsson

Statistical register's production and quality

National Medical Birth Register

The National Medical Birth Register contains information on pregnancies, deliveries and newborn babies in Sweden.

Reference period

Annual preparation of data on pregnancies leading to childbirth in Sweden and newborns from 1973. Corrections including late or adjusted data are made even after publication.

Table of contents

Production of the statistical register

F1 Context of the statistical register

The National Board of Health and Welfare maintains a number of personal ID number-based registers that are used as a basis for statistics and research on health care and social services. The National Medical Birth Register (MFR) is one of the National Board of Health and Welfare's health data registers. The MFR is an individual register whose population consists of pregnant women whose pregnancy leads to delivery in Sweden, and their newborn children.

F2 Design

F2.1 Outline of register content

The MFR is based on medical records from maternity and obstetric care. The register contains information on factors related to pregnancy and labour, such as women's age and body mass index (BMI), tobacco use, number of previous deliveries, etc. There is also information on the delivery, including the length of the pregnancy, pain management, mode of delivery, incidence of serious obstetric ruptures, etc. For the newborn child, there is information on the type of birth (single or multiple birth), the weight and length of the child and survival. For both the mother and the child, information is available on diagnoses and treatment procedures in connection with the birth.

The personal ID numbers of the mother and child, the mother's place of residence, and country of birth are also included.

F2.2 Data sources

The MFR is based on a sample of the data recorded by health care providers in patient records, during maternity care and obstetric care visits (see also F2.4.2 Measurement). The data recorded in maternity care is partly self-reported data that is collected through a health declaration completed by the woman upon enrolment or which is given orally to the midwife, and partly the midwife's ongoing registration during visits to the clinic. The diagnosis data included in the maternity health data are self-reported and refer to diseases diagnosed before the current pregnancy (e.g., the variables DIABETES or ASTMA). In contrast, data from obstetric care are almost exclusively recorded by the health care provider (i.e., not self-reported), such as diagnosis codes for the mother and the baby, procedures related to the delivery or pain management methods.

In the list of variables, the Origin column indicates the source of a given variable; MHV1 and MHV2 for data coming from maternity care (upon enrolment in maternity care and around week 32 of pregnancy, respectively) and FV1 and FV2 for data recorded in obstetric care (about the birth and the child, respectively).

Additional information is then linked from the Total Population Register (RTB) provided by Statistics Sweden (SCB), including the child's personal ID number (see K2.2.4 Processing), the place where the mother was registered at the time of birth, and the mother's country of birth. Information regarding date of death of the child is obtained from the National Cause of Death Register (National Board of Health and Welfare).

The information is stored in the register as one item (observation) per child born. In multiple births, where there are several records, the mother's data are duplicated.

F2.3 Time frame

The National Medical Birth Register is updated once a year with a new annual stock of births. Data on pregnancies, deliveries and newborns are continuously reported to the National Board of Health and Welfare by regions and healthcare providers throughout the year. The frequency of reporting varies between regions - from monthly reporting to reporting a couple of times a year. There is no set deadline for data delivery. Additions and corrections are made on an ongoing basis until the register is deemed to be of sufficient quality, according to an overall assessment, and is then made available. A given year's data are usually compiled and made available at the end of the following year, or the beginning of the year after.

Updates and corrections occur even after an annual constituency is first made available, but to such a limited extent that it should not affect register use.

F2.4 Collection procedure

F2.4.1 Data collection methods and data providers

The obligation to report data to MFR exists for those who conduct activities in the health care sector, and is regulated by the Health Data Register Act (1998:543) and the associated regulation (2001:708). Unlike the National Board of Health and Welfare's other health data registers, there are currently no regulations governing how and when data must be delivered.

All regions report data recorded in patient records in maternity and obstetric care. In the few cases where reporting is done on paper, it is the respective maternity hospital that sends data (see Table 1 for a summary of reporting methods per region). These paper forms are scanned at the National Board of Health and Welfare. Previously, data from paper forms were entered manually.

The method used for extracting data from patient record systems differs between healthcare providers based on their IT technologies. All regions that report electronically, with one exception, report via the National Board of Health and Welfare's SFTP service. Dalarna reports via SHS (*Spridnings- och Hämtningssystem*). All files delivered are uniformly formatted comma-separated text files or fixed-width text files.

Table 1 List of regions and how they report to the MFR

Regions	Type of delivery	Record system	Started e-reporting
Blekinge	Paper forms	*Obstetrix*	-
Dalarna	Electronic reporting	*Obstetrix*	2008
Gävleborg	Electronic reporting	*Obstetrix*	2020
Halland	Electronic reporting	*Obstetrix*	2016
Jämtland	Electronic reporting	*Obstetrix*	2012
Jönköping	Electronic reporting	*Obstetrix*	2013
Kalmar	Electronic reporting	*Obstetrix*	2008
Kronoberg	Electronic reporting	Cosmic	2012
Norrbotten	Paper forms	Partus	-
Skåne	Electronic reporting	*Obstetrix*	2013 (Kristianstad 2008)
Stockholm (also reports Gotland)	Electronic reporting	*Obstetrix*	2008
Södermanland	Electronic reporting	*Obstetrix*	2015
Uppsala	Electronic reporting	Cosmic	2012
Värmland	Electronic reporting	Cosmic	2015
Västerbotten	Electronic reporting	*Obstetrix*	2007
Västernorrland	Electronic reporting	*Obstetrix*	2007
Västmanland	Electronic reporting	*Obstetrix*	2020
Västra Götaland	Electronic reporting	*Obstetrix*	2017
Örebro	Electronic reporting	*Obstetrix*	2008
Östergötland	Electronic reporting	*Obstetrix*	2015

F2.4.2 Measurement

Until 1982, reporting to the register was done in most of the country by means of a so-called medical birth notice, which summarised the relevant medical records. Data collection changed in 1982 when the register began to be based on the medical record forms for maternity and obstetric care designed by the National Board of Health and Welfare. The latest version was designed in 1998 (see Annex 1). Reporting to the MFR was done on these paper forms until healthcare providers started sending data digitally. The patient record systems used in maternity and childbirth care today are to some extent a digitization of the National Board of Health and Welfare's record forms. Therefore, there is a clear link between the design of these record forms and the structure of the MFR, e.g., how variables are constructed (see also F2.5.1 Coding).

F2.4.3 Defective deliveries

There are established procedures for deliveries, and the National Board of Health and Welfare has regular contact with data providers. A variety of measures are being taken to reduce both item non-response and partial non-response. What follows is a description of the procedures that have been followed with minor changes in recent years, and there is no complete description of the corresponding controls used over time since the start of the register.

After each electronic file delivery, feedback is sent to the informant with a summary of the delivered data, including a summary of the number of reported births compared to previous deliveries. Partial non-response is also reported, for those variables where non-response can be calculated. Different colour markings

are used to highlight major non-response. The informant is asked to confirm that the information is correct or to correct it.

Furthermore, since 2015, a volume control of the number of reported births per hospital is carried out three times a year. The feedback is sent to the regions for approval. At the end of March of the year following the reference year, a comparison is made of the number of births reported compared to the previous year. If the number of reported births in a region differs significantly from the previous year, indicating that the reporting is not complete, a reminder letter is sent to the informant.

Later in the year, the births reported to the MFR are matched with SCB's data on children born in the same year (Total Population Register -RTB), which is based on the Swedish Tax Agency's population registration database. For children not reported to the MFR, information on the hospital where they were born can be obtained by cross-checking with the National Patient Register, and the region concerned can then be contacted to request completion. Previously, these missing birth searches were done only for perinatally dead babies, but since 2014 (children born in 2014) they are done for all births. For a further description of how incoming data are checked, and the actions taken, see F2.5.3 Reasonability checks.

The National Board of Health and Welfare has limited knowledge of the audits and quality controls carried out by the informant.

F2.5 Processing with review

F2.5.1 Coding

Diagnoses in the register (both for the mother and the child) are coded according to ICD-10-SE[1] and its previous editions (see Table 2 below). The coding is done before the data are received by the National Board of Health and Welfare. Any procedures are coded according to the KVÅ classification[2]. This coding is also done before the data is received.

Table 2 Coding system used for diagnosis coding in the medical birth register

Year	ICD version
1973-1986	ICD-8
1987-1996	ICD-9
1997	ICD-9 for Skåne County Council, ICD-10-SE for the others
1998-	ICD-10-SE

Since 1997, the Swedish Society of Obstetrics and Gynecology (SFOG) has published a diagnostic manual containing their recommendations for the use of diagnostic and procedure codes[3]. Code texts may differ in some cases between the diagnostic manual and ICD-10-SE. One example is the code O67.8. The code text according to ICD-10-SE is *Other haemorrhage during childbirth*, while the

[1] The Swedish version of ICD-10 (International Statistical Classification of Diseases and Related Health Problems 10th Revision). https://www.socialstyrelsen.se/utveckla-verksamhet/e-halsa/klassificering-och-koder/icd-10/
[2] Klassifikation av vårdåtgärder (Classification of Health Care Procedures) (KVÅ). https://www.socialstyrelsen.se/utveckla-verksamhet/e-halsa/klassificering-och-koder/kva/
[3] *Diagnoshandbok för kvinnosjukvården* (Diagnostic Manual for Women's Health Care). https://www.sfog.se/start/raadriktlinjer/diagnoshandboken/

code text in SFOG's diagnostic manual in 2020 is *Abundant haemorrhage during caesarean section >1000 ml (surgical haemorrhage)*.

There are also register-specific codes in the MFR that are originally derived from the medical record forms on which the collection is based (see F2.4.2 Measurement). Record keeping is largely based on checkboxes and predefined lists, less so on free text. These checkboxes and lists are directly translated into variables in the MFR. For example, if the checkbox for induction is ticked in the journal, this translates to FLINDUKT=1. The selection of "Vertex/crown presentation (occiput anterior)" in a drop-down list in the record is translated into "1" in the variable BJUDNING. Furthermore, the options 'Cephalic (occiput posterior)' and 'Breech or foot presentation' are translated as '4' and '6' respectively, etc.

Information about a diagnosis/procedure, for example, can be available both as a register-specific code (originating from a checkbox/list) and as an ICD/KVÅ code. One example is epidural anaesthesia (EDA), which can be entered with EPIBL=1 (variable derived from checkbox), or with the KVÅ codes SN Epidural anaesthesia or ZXH50 Epidural anaesthesia. Some patient record systems also have the ability to automatically generate diagnosis codes from checked boxes and predefined lists.

For many register-specific codes, it is necessary to supplement data from ICD and KVÅ codes to obtain complete information. For example, Skåne has more than 40 per cent non-response on the variables for termination of labour (non-response on VAGINAL, SECAVSL, TANG and SUGKLOCK) over a ten-year period (the non-response came from two hospitals with more than 70 per cent non-response), but for almost all these births there is instead an ICD or KVÅ code indicating how the labour was terminated.

It may also be necessary to use information from ICD/KVÅ codes to resolve conflicting information in the register-specific variables. Many of them are constructed as separate variables for each response option, making it possible to select multiple options even though they are mutually exclusive. For example, when, according to the variables for labour termination (see above), labour was terminated both vaginally (VAGINAL=1) and by caesarean section (SECAVSL=1). However, such contradictory combinations of variable values are very rare in recent years.

In some cases, new variables are created by the National Board of Health and Welfare combining different sources of information, in order to simplify for the register user. One example is the variable SECMARK, which indicates whether the labour was terminated by caesarean section. It is created from a number of register-specific variables indicating how labour was started/terminated and from the mother's ICD and KVÅ codes. This allows the register user to identify a caesarean delivery without extensive data processing or knowledge of appropriate codes to search for. For a detailed description of the variables, see the list of variables.

Data on medicine use during pregnancy are reported to the register in free text. At the National Board of Health and Welfare, these are processed and translated into ATC codes.

F2.5.2 Duplicate check

A check is made to see if the same personal ID number of the child appears several times in the register. Even if the child's personal ID number is missing, duplicates can be detected by producing records that have identical information on a set of variables that should not be identical (same date of birth of the child,

same birth weight, height, head circumference, etc.), and are therefore likely to be duplicates.

F2.5.3 Reasonableness check

Several different checks on the plausibility of the reported data are carried out at the National Board of Health and Welfare. One type of check is whether the values of the variables fall within a logical range, i.e., they are not unreasonably low or high (e.g., weight of the mother or height of the child at birth). For many variables, values that fall outside a permitted range are automatically blanked.

Since 2018 (children born in 2018), systematic data quality checks (acceptance tests) are carried out before a new annual stock is made available. The data were acceptance tested previously, but to a much more limited extent. There are three types of controls on a selection of key variables (mainly those used in official statistics on pregnancies, births and newborns). The checks are carried out at regional level in order to provide feedback to the informant as necessary. The first type of check is to compare the prevalence of a certain phenomenon with previous years (e.g., rate of premature births or rate of obese mothers), to detect unreasonable increases or decreases that may be due to misreporting. Another type of check is if there are unreasonable combinations of values, e.g., a birth has been completed both vaginally and by caesarean section. Finally, non-response in different variables is also checked by region and compared with previous years.

When inaccuracies are detected, in some cases they can be corrected after contacting the informants, in other cases invalid/unreasonable values are cancelled. With the new quality checks for 2018, retrospective errors were also detected, which in many cases could be corrected.

F2.5.4 Imputations

No imputation is made as a result of missing objects, i.e., missing whole births.

Information on tobacco use before pregnancy and in early pregnancy: If a snuff variable is blank while the smoking variable (for the corresponding period of pregnancy) is filled with a value, the value 0 (no snuff) is imputed. Similarly, the value 1 (non-smoker) is imputed if the variable is empty while there is a value in the snuff variable. This is due to the design (layout) of the record form (see F2.4.2 Measurement), where the mother's tobacco habits are a continuous item. The design makes it possible to assume that the person has answered the whole tobacco section by filling in one of the variables, either snuff or smoking. Thus, a blank value can be replaced by no snuff use/non-smoker. The table below shows the impact of imputation on non-response in 2019:

Table 3 Non-response in variables on tobacco use three months before and in early pregnancy

	Before imputation	After imputation
ROK0	2.75%	1.97%
ROK1	2.75%	2.03%
SNUS0	1.99%	1.97%
SNUS1	2.07%	2.03%

F2.5.5 Model-based calculations

Some variables are derived from other variables in the register with some elements of calculation. GRDBS and GRVBS are estimates of the length of pregnancy based on, among other things, the estimated date of delivery according to ultrasound.

The variables MSGA (small for gestation age) and MLGA (large for gestation age) indicate whether the baby weighs little/much in relation to the length of the pregnancy. The estimates are based on a growth curve that takes into account the child's sex, birth weight (grams) and length of pregnancy (days) and includes only single births.

For a more detailed description of these variables, see the list of variables.

F2.5.6 Comparisons with other registers and data sources

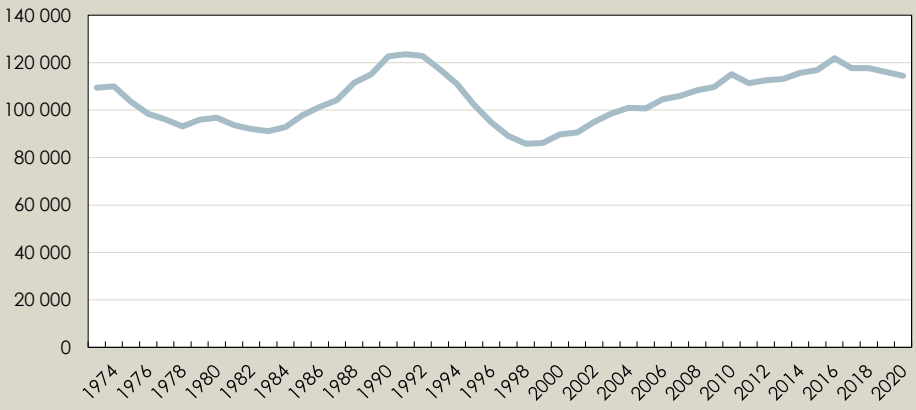
The births reported to the MFR are compared with live births and stillbirths according to the register of the Total Population Register (RTB), provided by Statistics Sweden. For a more detailed description see F2.4.3 Deficiencies in deliveries.

F3 Implementation

F3.1 Quantitative information

Since 1973, the number of reported births per year has ranged from just over 80,000 to around 120,000, as illustrated in Figure 1.

Figure 1. Number of live births registered in MFR, 1973–2020



Source: the National Medical Birth Register, National Board of Health and Welfare

F3.2 Deviations from the design

No significant deviations from the design have been made.

Statistical register quality

K1 Relevance

K1.1 Objectives and information needs

K1.1.1 Register objective

The main purpose of the register is to produce register-based statistics regarding pregnancies, deliveries and newborns. The data in the Register is used as a basis for Swedens official statistics on pregnancies, deliveries and newborn infants, development work in health care and for research.

K1.1.2 Information needs of register users

The register is primarily used to describe events and outcomes for women and children during pregnancy, labour and the neonatal period. Statistics based on the register are used by government agencies, regions, municipalities, hospitals, media, the public and others. The register provides the basis for official statistics on pregnancies, deliveries and newborns. The register also provides an important basis for research. Research based on the register can answer questions such as how different factors during pregnancy affect the course of labour and the newborn baby. Another important question is how childbirth and early life factors affect the child's future health (along with other records). It is also possible to describe how different phenomena, such as caesarean section rates and high BMI, have developed over time and how they differ between different groups in the population, etc.

K1.2 Register content

K1.2.1 Object and population

The target and observation objects of the register are deliveries and newborn babies in Sweden. The target population is all women giving birth and all children born in Sweden during one reference period (one calendar year). Stillbirths are included in the National Medical Birth Register if they have a gestational age of at least 22+0 weeks, that is 22 complete weeks plus 0 days (before 1 July 2008, stillbirths were included from week 28+0). The target population includes all women regardless of population-registration status at the time of delivery. Swedish women giving birth abroad are not included. Pregnancies that did not lead to delivery, i.e., ended with induced abortion or miscarriage, are not included.

K1.2.2 Variables

The register contains information about the mother that may be relevant to the pregnancy, such as smoking habits and BMI. It also contains information about the delivery, including the length of the pregnancy, pain management, mode of delivery, type of birth (single or multiple birth) and the newborn baby (weight, height, survival, diagnoses, etc.). Personal ID numbers are available for both the mother and the child. For a detailed description of the variables included, see the list of variables.

The variable content was last updated in 1999, which means that there may be some discrepancy between what the variables cover and factors that are important in modern obstetric care.

Please note that information on alcohol intake during pregnancy is not included in the register, as it is personal data that may not be processed according to the Ordinance on the medical birth register (2001:708) at the National Board of Health and Welfare[4].

[4] The personal data that may be processed within the framework of the medical birth register is set out in Section 4 of the Ordinance on the medical birth register (2001:708) at the National Board of Health and Welfare.

There is no specific information in the register on diagnoses made during pregnancy, unless they are listed as diagnoses at birth. This makes it inappropriate to track data on, for example, gestational diabetes or pre-eclampsia using the register. These may be listed as obstetric diagnoses given their relevance to labour, but this is not always the case (as they should not be explicitly listed).

K1.2.3 Reference times

The National Medical Birth Register is based on the annual stock of births, i.e., births that took place in a given calendar year.

Maternity care variables relate to different times during, and in some cases before pregnancy. For example, tobacco use three months before pregnancy and at enrolment in maternity care. The reference time for each variable is shown in the list of variables.

K2 Reliability

K2.1 Overall reliability

The reliability of the register is mainly determined by the patient record systems on which the register is based, as well as the administrative procedures of the healthcare providers. The National Board of Health and Welfare has limited knowledge regarding the informants' administrative procedures - how and when data are entered and by whom, how data are checked, etc. These factors have likely varied over time and differ between hospitals. Similarly, knowledge is lacking regarding the support functions available in the various patient record systems, e.g., whether warnings appear in case of unreasonable, invalid or missing values.

Errors can arise when informants extract data from their administrative systems, or when they are uploaded to the National Board of Health and Welfare. Errors can arise in reporting from regions with electronic reporting as well as those reporting on paper, but have generally been much lower with electronic reporting.

The overall assessment is that the register is of good quality. Non-response for reported births is low, representing about 1-3 per cent of the country's births per year over the last 20 years. However, reliability depends on what is being studied, as it differs between different variables, over time and between different informants. See more information under each source of uncertainty below.

K2.2 Sources of uncertainty

K2.2.1 Coverage

To estimate the degree of coverage, the reported births in the MFR can be matched with the child's personal ID number to children born in Statistics Sweden's Total Population Register (RTB). RTB data are based on the population register at the Swedish Tax Agency, and the comparison can therefore only be made for children who are registered in Sweden[5]. In addition, a complete personal ID number must be registered in order to make the connection.

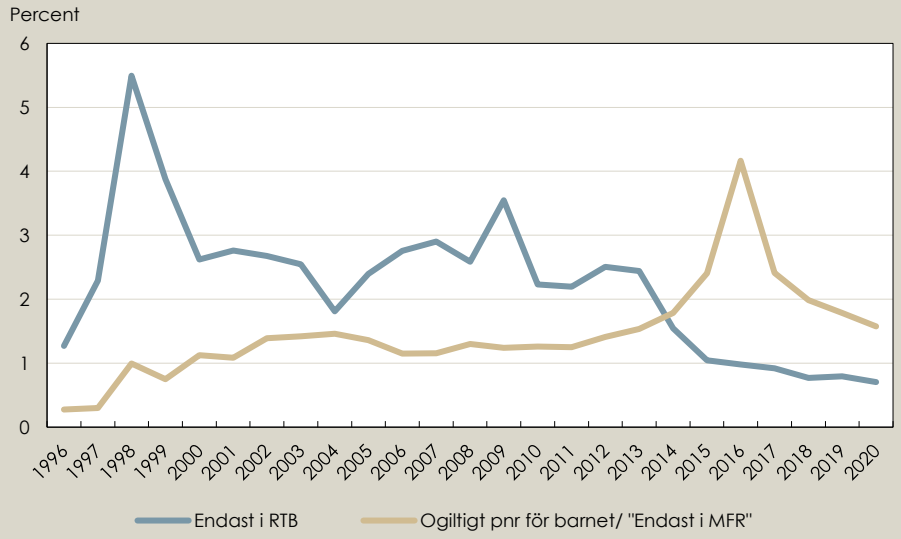
The comparison shows an underreporting to the MFR of about 1-3 per cent per year over the last 20 years for live births (see Figure 2). In 1998, just over 5

[5] According to section 2 of the Population Registration Act (1991:481): "A child born alive in this country shall be registered if the mother is registered or if the father is registered and has custody".

per cent of births were missing, due to a high non-response rate from one hospital. In 2014, underreporting decreased further, and since 2015 it has been below 1 per cent.

Unlike the RTB, the MFR includes all births taking place in Sweden, regardless of whether the child is registered in the country. This results in the MFR having more births than the RTB in some years, especially in years of higher immigration, as the number of unregistered people is higher (e.g., in 2016). In Figure 2, invalid personal ID numbers for the child are used as a proxy for the fact that the child is not registered and that the birth is therefore only available in the MFR and not in the RTB.

Figur 2. Number of live births registered only in MFR and RTB respectively



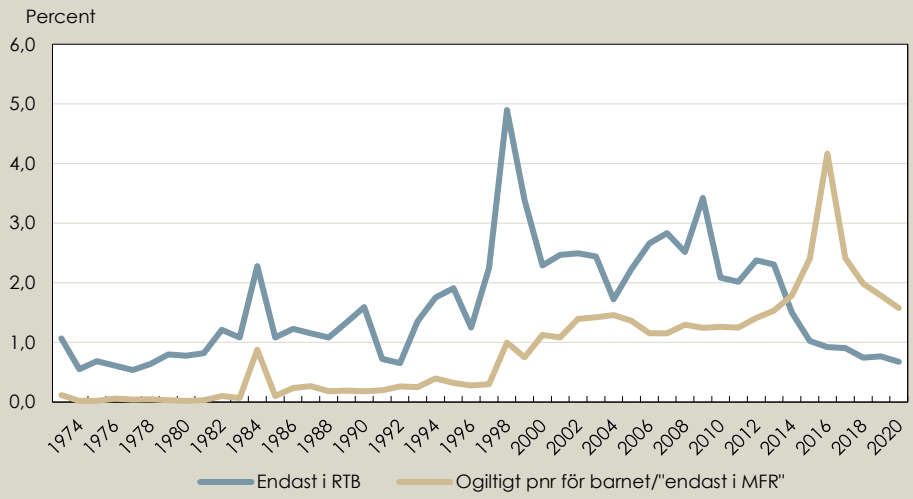
Source: the National Medical Birth Register, National Board of Health and Welfare; Total Population Register, Statistics Sweden

The coverage shortfall in the graph (RTB Only) is slightly overestimated because a missing personal ID number does not necessarily mean that the birth is missing from the MFR. The birth may be in the register, but with an invalid personal ID number for the child and therefore not matched. One example is births where only the father is registered. These are often given invalid personal ID numbers in the MFR even though the child is registered. These births also cause a corresponding overestimation of the proportion of Invalid personal ID number child /"only in MFR".

Another way of estimating the coverage shortfall in the MFR is to compare the number of children born in the MFR and the RTB during the same time period, i.e., without matching personal ID numbers. Children with invalid personal ID numbers (proxy for un-registered) need to be excluded from the MFR in order to be comparable with the RTB. The difference in the number of births can then be interpreted as the coverage shortfall of the MFR. The comparison will be less precise than if personal ID numbers are matched, but then it is possible to

estimate the coverage rate all the way back to the start of the register. See Figure 3 Births found 'only in the MFR' are calculated in the same way as in Figure 2, i.e. the number of births with an invalid personal ID number for the child.

Figur 3. Jämförelse antal levande födda MFR* och RTB



* Endast födslar med fullständiga personnummer för barnet

Källa: Medicinska födelseregistret, Socialstyrelsen; registret över totalbefolkningen, SCB

Since the reporting to the MFR is based on the reporting of maternity and obstetric care, this means that only deliveries that take place within the health care system will be included. It is rare for a birth to take place without any contact with the health care system (during or afterwards), but in these cases the birth would not be recorded in the MFR. Planned home births must be reported by the midwife attending the birth, but it is uncertain how much non-response there is in this reporting. Unplanned out-of-hospital deliveries are usually reported during subsequent health care visits.

K2.2.2 Measurement

Measurement errors can occur at different stages of the preparation of the register. Incorrect values can occur as a result of manual errors when entering information into the medical record systems. Errors may also occur in self-reported information (people may misremember or not answer truthfully), which could affect, for example, variables on smoking before and during pregnancy (reported by the pregnant woman at the maternity care enrolment visit). Furthermore, errors can occur in the medical record systems, especially when any change or update is made.

Before 1998, data from the delivered paper forms were entered into the National Board of Health and Welfare's computer system without any logical checks and the error rate was relatively high (e.g. the number of prohibited/incorrect values). In 2010, the National Board of Health and Welfare conducted a major review of data from this period, correcting what could be corrected and cancelling unreasonable values.

From 1999 onwards, recording was done in Microsoft Access, which had several logical checks at the time of entry and errors were significantly reduced. Errors were further reduced when the forms were scanned. Incorrect values have been significantly reduced with electronic reporting.

When the National Board of Health and Welfare reviews the data received, unreasonable or contradictory data may be noted, as well as invalid values. Otherwise, erroneous values are not detectable unless they are so common that they are visible in statistical summaries (e.g., an average or a proportion that differs significantly from other years). Thus, the degree of measurement error is ultimately unknown.

K2.2.3 Non-response

Non-response in individual variables has decreased significantly for most regions after the transition to electronic reporting. Non-response is generally higher for maternity data than for obstetric data. In Region Halland, it is more common with total loss of maternity data compared to other regions, which is probably due to the fact that maternity care visits have taken place in a region separate from the delivery centre.

In 2012, Värmland had almost 60 % non-response for many maternity health data items, such as maternal height and weight and the tobacco variables. In 2012 there was a change of medical record system which probably affected the quality of the data. The region was unable to report to the MFR for a couple of years. Data for 2012 and 2013 were reported retrospectively.

Some mothers lack a personal ID number, which contributes to partial non-response on demographic variables.

There is high non-response rate in the variables on tobacco use in late pregnancy, especially for snuff use. The non-response rate for snuff use in late pregnancy has increased in recent years, and in 2019 most regions had a non-response rate of more than 90 per cent. The total non-response rate for the country has been around 70-80 per cent since 2015. This is due to a system error in the medical record system used by most regions (*Obstetrix*) and has increased as these regions have moved to electronic reporting.

Non-response rates for smoking in late pregnancy differ to a greater extent between regions. In 2019, non-response was 40 per cent in Uppsala and Norrbotten, and 25 per cent in Halland. In other regions, non-response rates ranged from 4 to 15 per cent. In this case, the non-response is likely to be due to the fact that the data have not been recorded in maternity care from the beginning, as the problem occurs in both paper and electronic reporting.

See the list of variables for a description of the non-response of each variable over time, as well as Annex 2 Non-response variables of the MFR by region and year (covering only a selection of variables).

However, for many variables it is not possible to measure non-response due to the way they are constructed. For example, the variables KLIPP, which indicates whether an episiotomy was carried out during delivery, or EPIBL, which indicates whether an epidural was used for pain relief. It is not possible to determine whether the absence of a value in those variables means non-response or an episiotomy was not performed/epidural was not used. About half of the 200 or so variables in the MFR are constructed in the same or similar way, so that non-response cannot be calculated.

The register has a limit of 12 diagnosis codes and 12 procedure codes for one birth, and no more can be reported. This would result in the loss of diagnosis/procedure codes in cases where more than 12 diagnoses/procedures have been entered for a birth.

Birth weight is considered such a key variable that non-response must be avoided as far as possible. Supplementation of missing or unreasonable birth

weights (based on an overall assessment of the child's gestational age and diagnoses) is therefore routinely requested from informants. Supplementation may also be requested for other variables in individual cases, e.g., if a region has unusually high non-response in a particular year.

K2.2.4 Data processing

The child's personal ID number is generally not reported directly to the MFR. Previously, this was due to a delay in the allocation of a personal ID number to the child by the Swedish Tax Agency. Nowadays, the birth notification to the Swedish Tax Agency is done electronically and a personal ID number is assigned to the child immediately. Nevertheless, non-response for the child's personal ID number in the data delivered to the National Board of Health and Welfare is high. In 2019, around 13% of all births were delivered directly from the regions. The regions that use the *Obstetrix* medical record system and have electronic delivery (i.e., the majority, see Table 1) cannot deliver the child's personal ID number and the same applies to a region that reports on paper (*Partus* medical record system).

If the child's personal ID number is missing, it is obtained from Statistics Sweden's Total Population Register. However, the matching of personal ID numbers from Statistics Sweden is uncertain for same-sex multiple births, as Statistics Sweden does not have information on the birth order (different-sex multiple births can be distinguished using the penultimate digit of the social security number). Without information on the birth order, the personal ID numbers cannot be reliably matched with the information on the child in the MFR (birth weight, paediatric diagnoses, etc.). The consequence is that one twin can be attributed to the other twin's birth weight, diagnoses, Apgar score, etc. On the contrary, the second twin is linked to the characteristics of the first twin. The error occurs in about half of the cases for same-sex multiple births, as the matching is done randomly.

Since 2020 (children born in 2020), the National Board of Health and Welfare sends lists and asks informants to check whether the match with the personal ID numbers of same-sex multiple births has been correct and, if not, to correct it. A variable (BPNRQ_FB) has also been created to flag those multiple births where the personal ID numbers are uncertain (i.e., those of same-sex multiple births where personal ID numbers have been obtained from Statistics Sweden). Since 1973, it has varied between 45 and 70 per cent of the personal numbers for multiple births each year that are uncertain.

Minor adjustments are made to other variables in the register, but the changes are so small that the risk of error is low. This usually involves leaving invalid characters or unreasonable values blank.

K2.2.5 Modelling assumptions

Derivations and imputations are described under F2.5.3- F2.5.5.

K2.3 Provisional register compared to final register

Provisional versions of the register are not published.

K3 Timeliness and punctuality

K3.1 Preparation time

The preparation time of the register is about 11 months from the last birth for the reference year. Thus, for births at the beginning of the year, it takes just under two years for data to become available. Data on medicine use during pregnancy are usually only available a few months later due to the extensive processing involved in translating free text into ATC codes.

K3.2 Frequency

The register is updated annually. The collection of data is ongoing throughout the year.

K3.3 Punctuality

The National Board of Health and Welfare aims to make the register available by the end of the year following the reference year. For 2017 births, this was delayed by about five months due to delays in delivery to the register. For the 2018 births, the delay was about two months for the same reason and due to a problem with the scanning of paper forms.

K4 Accessibility and clarity

K4.1 Access to the register

MFR data may be disclosed for research and statistical purposes. Each request to the National Board of Health and Welfare for disclosure is subject to a confidentiality assessment. The National Board of Health and Welfare's statistical registers are subject to statistical confidentiality according to Chapter 24, Section 8 of the Public Access to Information and Secrecy Act (2009:400).

Aggregated data from the register are also available in the official statistics, in the National Board of Health and Welfare's statistics database, and through our commissioning activities.

K4.2 Dissemination of information

Information about the register can be found at socialstyrelsen.se. The official statistics on pregnancies, deliveries and newborns, based on the register, are published annually. The publication date is indicated in the publication calendar ofthe National Board of Health and Welfare.

K4.3 Documentation

The register is further documented on socialstyrelsen.se, including detailed descriptions of variables and value sets.

K5 Comparability and interoperability

K5.1 Comparability over time

In general, there are good opportunities for comparison over time. However, the variable content has changed over time - variables have been added, and in a few

cases removed. The biggest changes have occurred in connection with major revisions of medical records. The timeliness column in the list of variables provides information on the years in which a specific variable has existed.

The register includes live births and stillbirths with a gestational age of at least 22+0 weeks, i.e., 22 completed weeks plus 0 days. Before 1 July 2008, stillbirths were included from week 28+0). This change meant that the number of stillbirths increased.

Different versions of the ICD classification have been used in different years (see F2.5.1 Coding) which limits the possibility to compare the prevalence of certain diagnoses over time.

K5.2 Interoperability with other registers

The data in the MFR can be used with other registers based on personal ID numbers. When using them together, it should be kept in mind that there are some minor differences between the SFOG guidelines for the use of diagnosis and procedure codes and related descriptions (see F2.5.1 Coding), the established national ICD10-SE used in the National Patient Register and the international ICD10 used in the National Cause of Death Register. Regions may also have their own procedures regarding which codes to use and how. The timeliness of the MFR is also less than that of many other registers (between one and two years' delay), which makes it unsuitable for analysing acute events.

An example of shared use that is often relevant is in diagnosis and procedure codes for newborn babies in the National Patient Register. Diagnosis and procedure codes recorded in the National Medical Birth Register are in many cases not complete for critically ill or premature babies, who are often admitted directly to specialised care (neonatal care, paediatric clinic, etc.). In these cases, additional information may need to be obtained from the National Patient Register to get a more complete picture.

General information

U1 Confidentiality and personal data processing

In the special activities of public agencies for the production of statistics, confidentiality applies in accordance with Chapter 24, Section 8 of the Public Access to Information and Secrecy Act (2009:400). However, information needed for research and statistical purposes, we well as information that is not directly attributable to an individual through his or her name, other identity code or similar relationship, may be disclosed if it is clear that the information can be disclosed without causing damage or harm to the individual or someone close to him or her.

When processing personal data, i.e., information that can be directly or indirectly attributed to a living person, the General Data Protection Regulation 2016/679[6] and the Regulation (2018:218) containing supplementary provisions to the EU General Data Protection Regulation apply.

In addition, the Act regarding official statistics (2001:99), the Ordinance regarding official statistics (2001:100) and the the Health Data Register Act

[6] Regulation (EU) 2016/679 of the European Parliament and the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation).

(1998:543), as well as the Ordinance on medical birth registers (2001:708) at the National Board of Health and Welfare, , apply to the processing of personal data.

U2 Retention and data erasure

The MFR is a register where personal data must be exempt from data erasure. The register is covered by the Swedish National Archives' Regulations regarding exemptions from data erasure and data erasure at the National Board of Health and Welfare (RA-MS 2020:22) (*Föreskrifter om undantag från gallring och gallring hos Socialstyrelsen*). Primary data, i.e., the basis for the register, may be erased five years after the basis has been received by the public agency. However, the National Board of Health and Welfare's enforcement decision[7] of RA-MS 2020:22 states that primary data for the MFR must be preserved.

The register is a so-called living register, which means that continuous updates can change data even historically. Immediate erasure of incorrect data is permitted under RA-MS 2020:22, which means that earlier versions of the register are generally not saved by the National Board of Health and Welfare.

U3 Obligation to give information

Anyone conducting activities in the healthcare sector is obligated to give information to the National Board of Health and Welfare in accordance with the Health Data Register Act and the MFR Regulation.

U4 International reporting

Statistics from the medical birth register are reported to, among others, WHO, OECD, Eurostat, NOMESKO, Euro-Peristat and NOMBIR.

U5 History

The National Medical Birth Register was launched on 1 January 1973. The basis for the register was the introduction of a standardised medical record system in maternal, obstetric and neonatal care. Until 1982, reporting to the register was done in most of the country by means of a so-called medical birth notice, which summarised the relevant medical records. A copy of the summary was sent to the National Board of Health and Welfare and formed the basis of the medical birth register. During the 1980s and 1990s, the content and collection methods of the register were gradually revised. Since 1995, the medical birth register contains data from maternity care records (in early and late pregnancy), as well as from obstetric records for mother and child.

U6 Contact details

Questions regarding the National Medical Birth Register can be sent to the functional mailbox of the *Reproduktion och läkemedel* team:
Unit: Statistik 1
E-mail: rela@socialstyrelsen.se
Telephone: 075247 3000

Version history

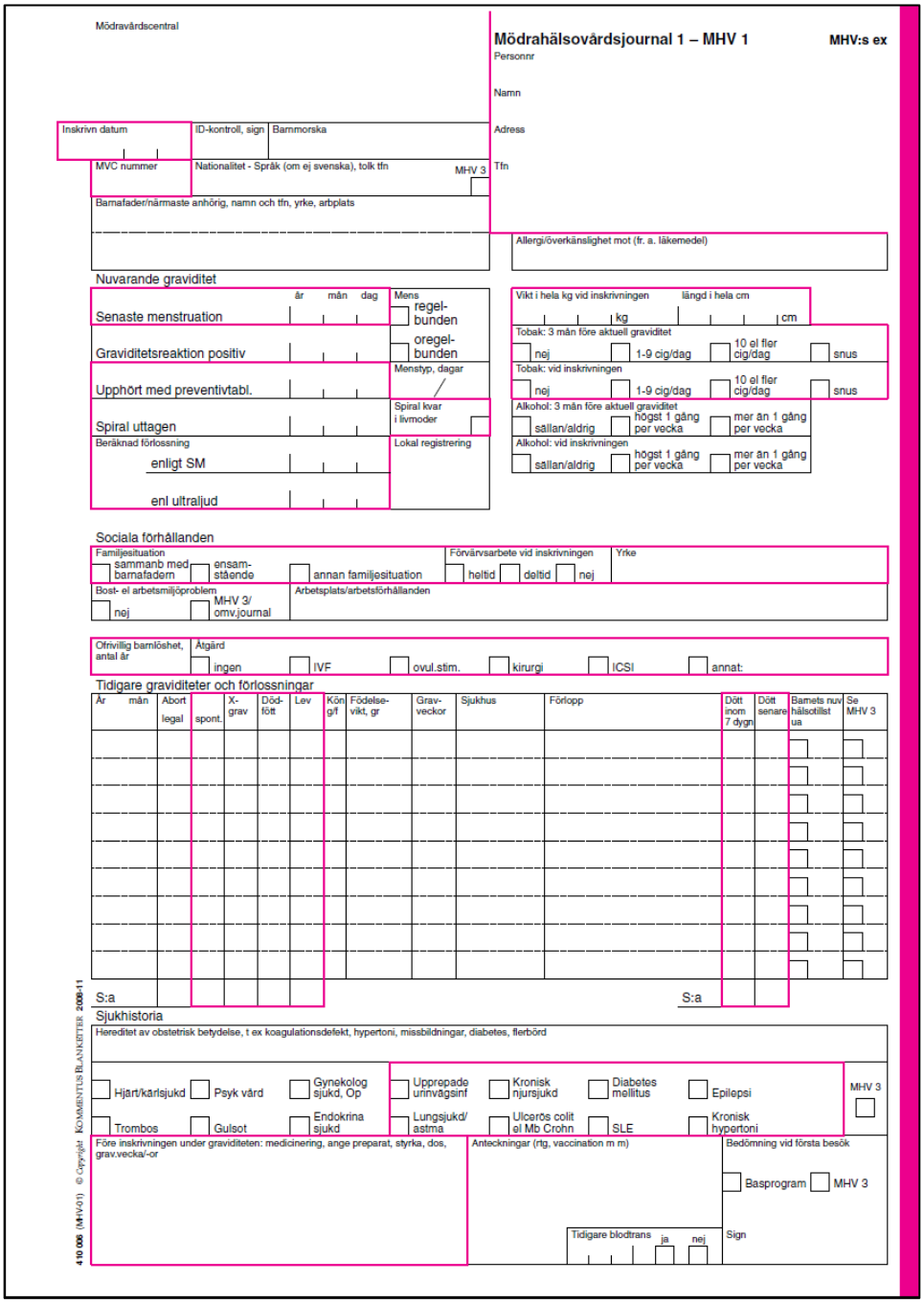
Version	Change	Date

[7] Decision registered with the National Board of Health and Welfare under number 1.3-26785/2020.

1.0	The document is new	14/09/2021
1.1	Figures 1, 2 and 3, and Annex 2 updated with 2020 data	18/02/2022

Annex 1 Maternal and obstetric care records

The fields highlighted/framed in pink are the information to be delivered to the National Medical Birth Register.



Mödravårdscentral

Mödrahälsovårdsjournal 1 – MHV 1 **MHV:s ex**

Personnr

Namn

Adress

Tfn

Inskrivn datum | ID-kontroll, sign | Barnmorska

MVC nummer | Nationalitet - Språk (om ej svenska), tolk tfn | MHV 3

Barnafader/närmaste anhörig, namn och tfn, yrke, arbplats

Allergi/överkänslighet mot (fr. a. läkemedel)

Nuvarande graviditet

Senaste menstruation (år mån dag) | Mens: regelbunden / oregelbunden

Graviditetsreaktion positiv

Upphört med preventivtabl. | Menstyp, dagar

Spiral uttagen | Spiral kvar i livmoder

Beräknad förlossning: enligt SM / enl ultraljud | Lokal registrering

Vikt i hela kg vid inskrivningen (kg) | längd i hela cm (cm)

Tobak: 3 mån före aktuell graviditet: nej / 1-9 cig/dag / 10 el fler cig/dag / snus

Tobak: vid inskrivningen: nej / 1-9 cig/dag / 10 el fler cig/dag / snus

Alkohol: 3 mån före aktuell graviditet: sällan/aldrig / högst 1 gång per vecka / mer än 1 gång per vecka

Alkohol: vid inskrivningen: sällan/aldrig / högst 1 gång per vecka / mer än 1 gång per vecka

Sociala förhållanden

Familjesituation: sammanb med barnafadern / ensamstående / annan familjesituation | Förvärvsarbete vid inskrivningen: heltid / deltid / nej | Yrke

Bost- el arbetsmiljöproblem: nej / MHV 3/ omv.journal | Arbetsplats/arbetsförhållanden

Ofrivillig barnlöshet, antal år | Åtgärd: ingen / IVF / ovul.stim. / kirurgi / ICSI / annat:

Tidigare graviditeter och förlossningar

År mån	Abort legal	Abort spont.	X-grav	Död-fött	Lev	Kön g/f	Födelse-vikt, gr	Grav-veckor	Sjukhus	Förlopp	Dött inom 7 dygn	Dött senare	Barnets nuv hälsotillst ua	Se MHV 3
S:a										S:a				

Sjukhistoria

Hereditet av obstetrisk betydelse, t ex koagulationsdefekt, hypertoni, missbildningar, diabetes, flerbörd

Hjärt/kärlsjukd / Psyk vård / Gynekolog sjukd, Op / Upprepade urinvägsinf / Kronisk njursjukd / Diabetes mellitus / Epilepsi

Trombos / Gulsot / Endokrina sjukd / Lungsjukd/ astma / Ulcerös colit el Mb Crohn / SLE / Kronisk hypertoni

MHV 3

Före inskrivningen under graviditeten: medicinering, ange preparat, styrka, dos, grav.vecka/-or

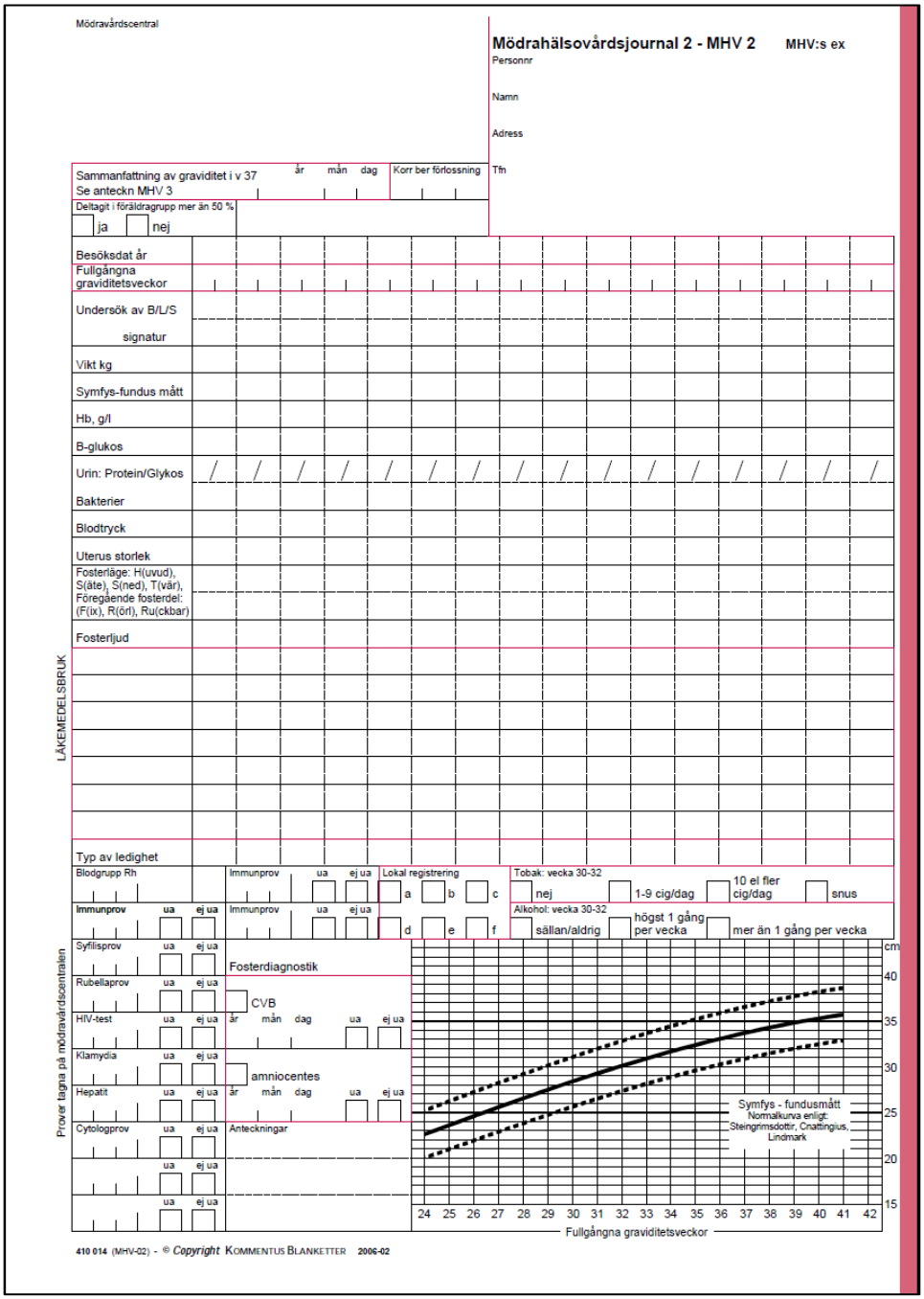
Anteckningar (rtg, vaccination m m)

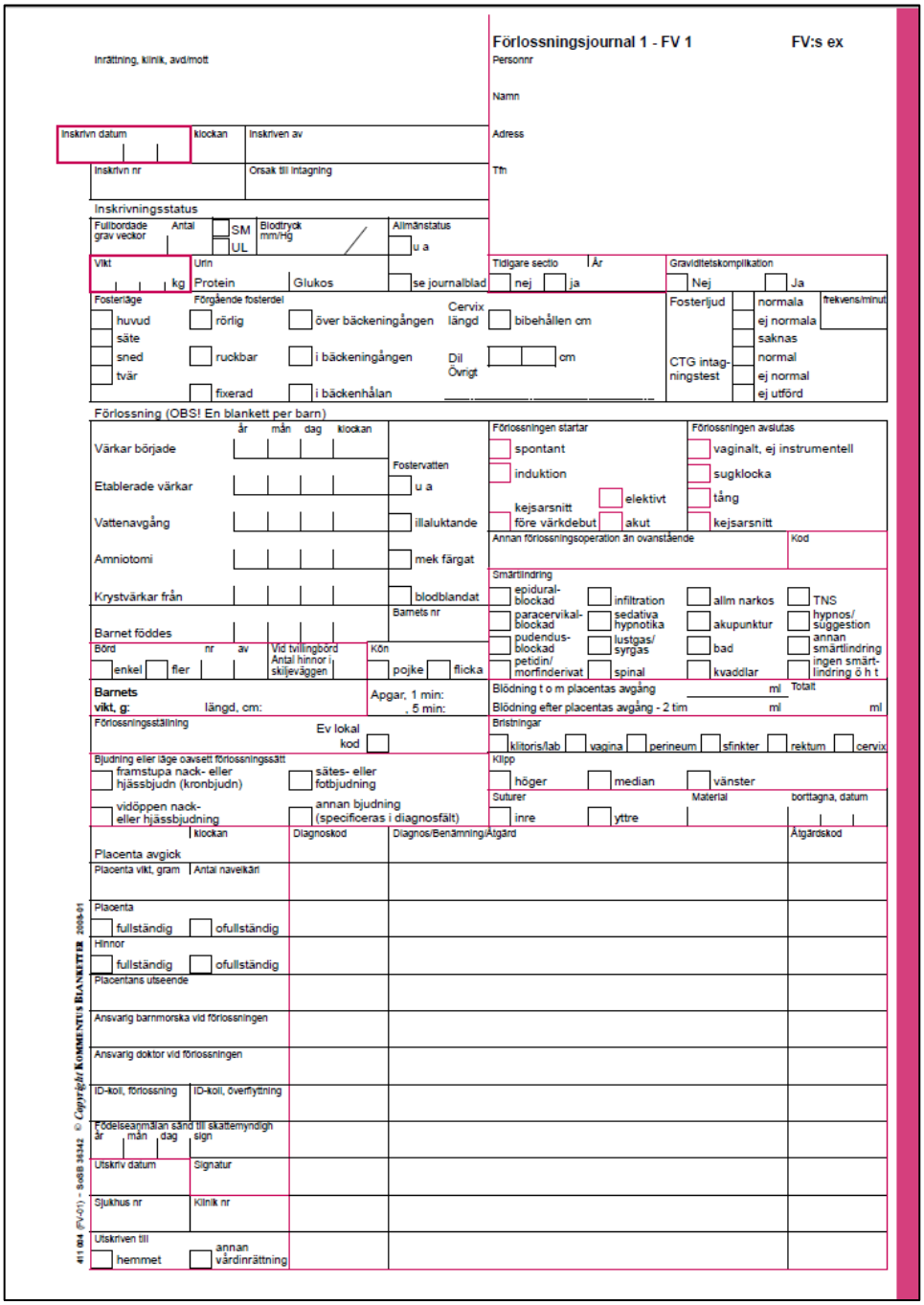
Bedömning vid första besök: Basprogram / MHV 3

Tidigare blodtrans ja nej

Sign

410 008 (MHV-01) © Copyright KOMMENTUS BLANKETTER 2008-11


Mödravårdscentral
Mödrahälsovårdsjournal 2 - MHV 2
MHV:s ex
Personnr
Namn
Adress
Tfn
Sammanfattning av graviditet i v 37
Se anteckn MHV 3
år mån dag
Korr ber förlossning
Deltagit i föräldragrupp mer än 50 %
ja
nej
Besöksdat år
Fullgångna graviditetsveckor
Undersök av B/L/S
signatur
Vikt kg
Symfys-fundus mått
Hb, g/l
B-glukos
Urin: Protein/Glykos
Bakterier
Blodtryck
Uterus storlek
Fosterläge: H(uvud), S(äte), S(ned), T(vår), Föregående fosterdel: (F(ix), R(örl), Ru(ckbar)
Fosterljud
LÄKEMEDELSBRUK
Typ av ledighet
Blodgrupp Rh
Immunprov
ua
ej ua
Lokal registrering
a
b
c
d
e
f
Tobak: vecka 30-32
nej
1-9 cig/dag
10 el fler cig/dag
snus
Alkohol: vecka 30-32
sällan/aldrig
högst 1 gång per vecka
mer än 1 gång per vecka
Syfilisprov
Rubellaprov
HIV-test
Klamydia
Hepatit
Cytologprov
Prover tagna på mödravårdscentralen
Fosterdiagnostik
CVB
amniocentes
år mån dag
Anteckningar
cm
40
35
30
25
20
15
24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42
Fullgångna graviditetsveckor
Symfys - fundusmått
Normalkurva enligt:
Steingrimsdottir, Cnattingius, Lindmark
410 014 (MHV-02) - © Copyright KOMMENTUS BLANKETTER 2006-02



Förlossningsjournal 1 - FV 1 FV:s ex

Inrättning, klinik, avd/mott

Personnr

Namn

Adress

Tfn

Inskrivn datum | klockan | Inskriven av

Inskrivn nr | Orsak till intagning

Inskrivningsstatus

Fullbordade grav veckor | Antal | SM / UL | Blodtryck mm/Hg | Allmänstatus: u a

Vikt kg | Urin: Protein | Glukos | se journalblad

Tidigare sectio | År | nej | ja

Graviditetskomplikation: Nej | Ja

Fosterläge: huvud | säte | sned | tvär

Förgående fosterdel: rörlig | ruckbar | fixerad

över bäckeningången | i bäckeningången | i bäckenhålan

Cervix längd: bibehållen cm

Dil: cm

Övrigt

Fosterljud: normala | ej normala | saknas | frekvens/minut

CTG intag-ningstest: normal | ej normal | ej utförd

Förlossning (OBS! En blankett per barn)

	år	mån	dag	klockan
Värkar började				
Etablerade värkar				
Vattenavgång				
Amniotomi				
Krystvärkar från				
Barnet föddes				

Fostervatten: u a | illaluktande | mek färgat | blodblandat

Barnets nr

Förlossningen startar: spontant | induktion | kejsarsnitt före värkdebut | kejsarsnitt elektivt | kejsarsnitt akut

Förlossningen avslutas: vaginalt, ej instrumentell | sugklocka | tång | kejsarsnitt

Annan förlossningsoperation än ovanstående | Kod

Smärtlindring: epidural-blockad | infiltration | allm narkos | TNS | paracervikal-blockad | sedativa hypnotika | akupunktur | hypnos/ suggestion | pudendus-blockad | lustgas/ syrgas | bad | annan smärtlindring | petidin/ morfinderivat | spinal | kvaddlar | ingen smärt-lindring ö h t

Börd: enkel | fler | nr | av

Vid tvillingbörd Antal hinnor i skiljeväggen

Kön: pojke | flicka

Barnets vikt, g: längd, cm:

Apgar, 1 min: , 5 min:

Blödning t o m placentas avgång ml Totalt

Blödning efter placentas avgång - 2 tim ml ml

Förlossningsställning

Ev lokal kod

Bristningar: klitoris/lab | vagina | perineum | sfinkter | rektum | cervix

Bjudning eller läge oavsett förlossningssätt: framstupa nack- eller hjässbjudn (kronbjudn) | vidöppen nack- eller hjässbjudning | sätes- eller fotbjudning | annan bjudning (specificeras i diagnosfält)

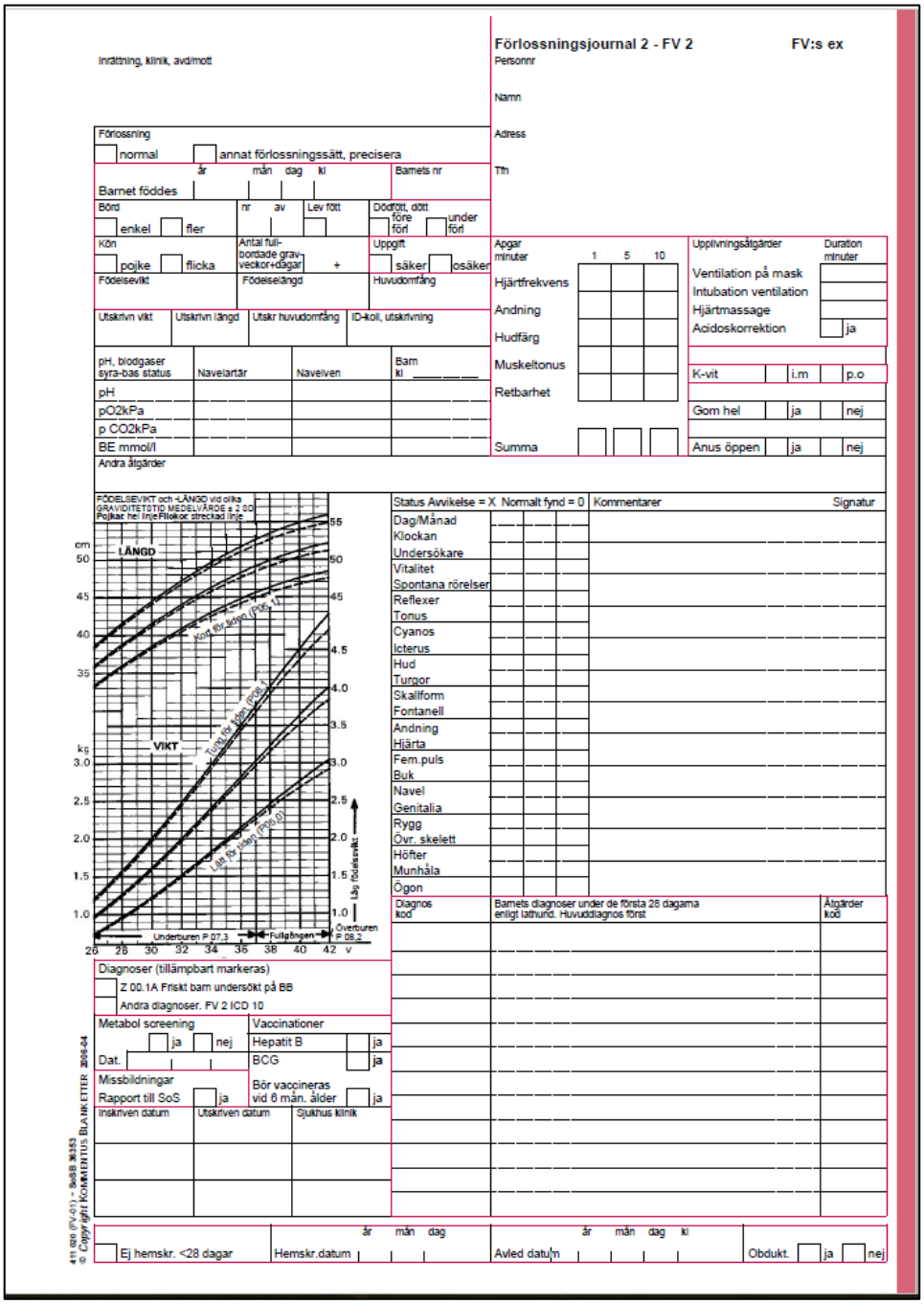
Klipp: höger | median | vänster

Suturer: inre | yttre

Material | borttagna, datum

	klockan	Diagnoskod	Diagnos/Benämning/Åtgärd	Åtgärdskod
Placenta avgick				
Placenta vikt, gram / Antal navelkärl				
Placenta: fullständig / ofullständig				
Hinnor: fullständig / ofullständig				
Placentans utseende				
Ansvarig barnmorska vid förlossningen				
Ansvarig doktor vid förlossningen				
ID-kod, förlossning / ID-kod, överflyttning				
Födelseanmälan sänd till skattemyndigh år mån dag / sign				
Utskriv datum / Signatur				
Sjukhus nr / Klinik nr				
Utskriven till: hemmet / annan vårdinrättning				

411 004 (FV-01) - SoSB 38342 © *Copyright* KOMMENTUS BLANKETTER 2008-01



Förlossningsjournal 2 - FV 2 FV:s ex

Inrättning, klinik, avd/mott

Personnr

Namn

Adress

Tfn

Förlossning
normal annat förlossningssätt, precisera

Barnet föddes år mån dag kl

Barnets nr

Börd enkel fler

nr av

Lev fött

Dödfött, dött före förl under förl

Kön pojke flicka

Antal fullbordade graviditetsveckor+dagar +

Uppgift säker osäker

Födelsevikt

Födelselängd

Huvudomfång

Utskrivn vikt

Utskrivn längd

Utskr huvudomfång

ID-koll, utskrivning

Apgar minuter 1 5 10
Hjärtfrekvens
Andning
Hudfärg
Muskeltonus
Retbarhet
Summa

Upplivningsåtgärder Duration minuter
Ventilation på mask
Intubation ventilation
Hjärtmassage
Acidoskorrektion ja

K-vit i.m p.o

Gom hel ja nej

Anus öppen ja nej

pH, blodgaser syra-bas status	Navelartär	Navelven	Barn kl _____
pH			
pO2kPa			
p CO2kPa			
BE mmol/l			

Andra åtgärder

FÖDELSEVIKT och -LÄNGD vid olika GRAVIDITETSTID MEDELVÄRDE ± 2 SD
Pojkar: hel linje Flickor: streckad linje

Status Avvikelse = X Normalt fynd = 0				Kommentarer	Signatur
Dag/Månad					
Klockan					
Undersökare					
Vitalitet					
Spontana rörelser					
Reflexer					
Tonus					
Cyanos					
Icterus					
Hud					
Turgor					
Skallform					
Fontanell					
Andning					
Hjärta					
Fem.puls					
Buk					
Navel					
Genitalia					
Rygg					
Övr. skelett					
Höfter					
Munhåla					
Ögon					

Diagnoser (tillämpbart markeras)
Z 00.1A Friskt barn undersökt på BB
Andra diagnoser. FV 2 ICD 10

Diagnos kod	Barnets diagnoser under de första 28 dagarna enligt Icd10rid. Huvuddiagnos först	Åtgärder kod

Metabol screening ja nej
Dat.

Vaccinationer
Hepatit B ja
BCG ja

Missbildningar
Rapport till SoS ja

Bör vaccineras vid 6 mån. ålder ja

Inskriven datum	Utskriven datum	Sjukhus klinik

Ej hemskr. <28 dagar

Hemskr.datum år mån dag

Avled datum år mån dag kl

Obdukt. ja nej

411 020 (FV-01) - 9x8B 36353 2006-04
© Copyright KOMMENTUS BLANKETTER

Annex 2 Non-response variables of the MFR by region and year (Excel document)

Document available for download at
www.socialstyrelsen.se/statistik-och-data/register/alla-register/medicinska-fodelseregistret/framstallning-och-kvalitet/