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METHODS

The Danish Medical Birth Register

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Abstract

The Danish Medical Birth Register was established in 1973. It is a key component of the Danish health information system. The register enables monitoring of the health of pregnant women and their offspring, it provides data for quality assessment of the perinatal care in Denmark, and it is used extensively for research. The register underwent major changes in construction and content in 1997, and new variables have been added during the last 20 years. The aim was to provide an updated description of the register focusing on structure, content, and coverage since 1997. The register includes data on all births in Denmark and comprises primarily of data from the Danish National Patient Registry supplemented with forms on home deliveries and stillbirths. It contains information on maternal age provided by the Civil Registration System. Information on pre-pregnancy body mass index and smoking in first trimester is collected in early pregnancy (first antenatal visit). The individual-level data can be linked to other Danish health registers such as the National Patient Registry and the Danish National Prescription Registry. The register informs several other registers/databases such as the Danish Twin Registry and the Danish Fetal Medicine Database. Aggregated data can be publicly accessed on the Danish Health Data Authority web page (www.esundhed.dk/sundhedsregistre/MFR). Researchers can obtain access to individual-level pseudo-anonymised data via servers at Statistics Denmark and the Danish Health Data Authority.

Keywords Registers · Research design · Medical record linkage · Nationwide birth register

Introduction

The Danish Medical Birth Register (MBR) is a key component of the Danish health information system. The register enables health of pregnant women and their offspring to be monitored as well as facilitate quality control of perinatal care. In addition, it provides data for Statistics Denmark and eSundhed.dk. These institutions provide aggregated annual data from the MBR available to the public as well as individual-level data for research. Data from the MBR is used alone or linked with other Danish register data in epidemiological research [1, 2].

The register was established in 1973 based on paper birth forms. The first systematic data collection started in 1968 and the first statistical analyses published; no electronic data was collected before 1973. Descriptive papers on the register have been published in 1986 [3] and in 1998 [4]. Major changes in construction and content of the register were implemented in 1997, with the paper from 1998 describing the old version [4]. In 1997, the electronic registration of births replaced paper forms and data has since been recorded in a slightly revised form to the Danish National Patient Registry (NPR) and fed directly into the MBR. The Danish National Patient Registry is a nationwide register which holds information on all somatic hospitalizations in Denmark since 1977. All psychiatric, outpatient, and emergency department contacts were added in 1995 [5]. Due to changes in clinical practice as well as a

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wish to add supplementary information, new variables have been added to the register during the last 20 years. Since then, the register has only been described briefly in papers within narrow specific research areas [6, 7] and in publications including medical birth registers from all Nordic countries [8, 9].

The aim of this paper is to provide an updated description of the register focusing on structure, content, and coverage since 1997, including a brief description of selected variables and the development over time. Further, we briefly describe the Danish legislation and how to access data from the MBR.

Historical background

The nationwide MBR was established in 1973, and data on all live and stillbirths by women with residence in Denmark giving birth in Denmark have been registered in the MBR since. The Danish Health Data Authority administers the MBR and all other Danish national health registers. Even before 1973, midwives recorded some structured information on maternal health, complications and interventions during pregnancy and delivery, and infant outcome in birth protocols. These protocols are kept in the Danish National Archives and from 1910 the registration is considered nearly complete (personal communication, the Danish National Archives: www.sa.dk).

Structure and content

The MBR holds medical and civil registration information. Since 1968, all residents in Denmark are registered in the Danish Civil Registration System with a unique 10-digit civil registration number (CPR number), which is used in all official registrations [10]. Thus, all newborns are assigned a CPR number at delivery in Denmark or upon immigration to Denmark. At assignment, the unique CPR number of the child is linked to the CPR number of the parents in the Civil Registration System [10]. Since 2002, stillbirths have also received a CPR number for administrative purposes. The Danish Civil Registration System holds information on migration, vital status and selected demographic data on the parents [10]. To be noted, parents in the MBR are the (assumed) biological parents, whereas the parents registered in the Danish Civil Registration System are the legal parents and thus not necessarily equivalent to the former (unless a paternity trial has been resolved).

The MBR comprises routinely collected data from the NPR [5] including additional specific variables on pregnancy, delivery, and outcome supplemented with demographic information from the Danish Civil Registration System and the content of separate forms on home births and stillbirth (Fig. 1). All conditions relevant for the pregnancy are reported to the NPR at the first antenatal contact. This includes information on maternal characteristics such as pre-pregnancy body mass index (BMI), smoking in the first trimester, and relevant comorbidities. During pregnancy and labour, midwives or medical doctors update information at each hospital contact [11]. By means of the unique individual CPR number, other Danish registers and clinical databases can easily be linked to the MBR.

A graphical presentation of the content of the MBR appears in Fig. 2. The MBR consists of a main table with index pregnancy (one line for each infant in the same pregnancy) as the key identifier and information on the identity on both parents by CPR number, pregnancy-related background characteristics of the mother including data on numbers of visits to health professionals, place of residence, parity, and potential risk factors in pregnancy including pregnancy-related complications. In addition, it holds details of the delivery including date, events during delivery such as disproportion, sign of asphyxia, epidural anaesthetic, assisted vaginal delivery, and caesarean section. Finally, it holds outcome characteristics of the newborn such as gestational age, Apgar score, birth weight, length, and head circumference. Any congenital abnormalities are retrospectively added to the table if identified within the first year of life. All subsequent health events reported by diagnoses and surgical interventions can be found in the NPR. All deaths of mother or infant within the first 365 days after delivery are registered including the age in days when the infant died.

Nineteen events and conditions are only indicated with binary indicator variables in the main table. For each indicator variable, a satellite table holds in-depth data based on the Danish Healthcare Classification System including International Classification of Diseases codes (version 10) (ICD-10) [12]. Detailed data on home deliveries and stillbirths can be found in separate tables which can be linked to the main table using a MBR key variable, unique for each observation in the main table. A translated list of the most frequently used variables is found in Table 1. An extended list can be found in Online Resource.

Most variables have been unchanged since 1997, however, new ones have been added and some have been redefined (Table 2). To be noted, until April 2004, the birth of a dead foetus before gestational week 28 + 0 was considered a miscarriage and therefore not registered in the MBR. From April 1st 2004, a dead foetus born after gestational week 22 + 0 is considered a stillborn child and is registered in the MBR. Thus, stillbirths between 22 and 28 weeks before April 2004 will be found only in the NPR. From 2004, regardless of gestational age, a newborn with any signs of life (breathing, heartbeat, pulsation in the

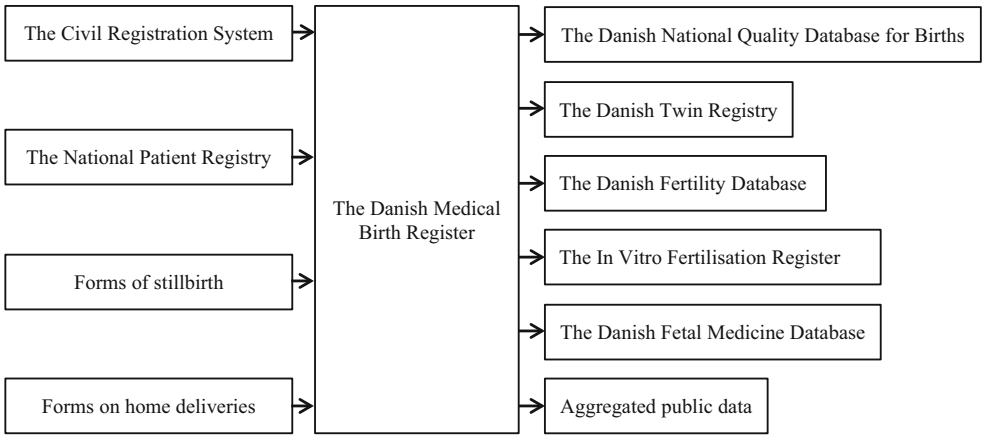

Fig. 1 Overview of data sources feeding into the Danish Medical Birth Register and registers/databases that the Danish Medical Birth Register feeds into. The list of registers/databases that the Danish Medical Birth Register feeds into may not be complete

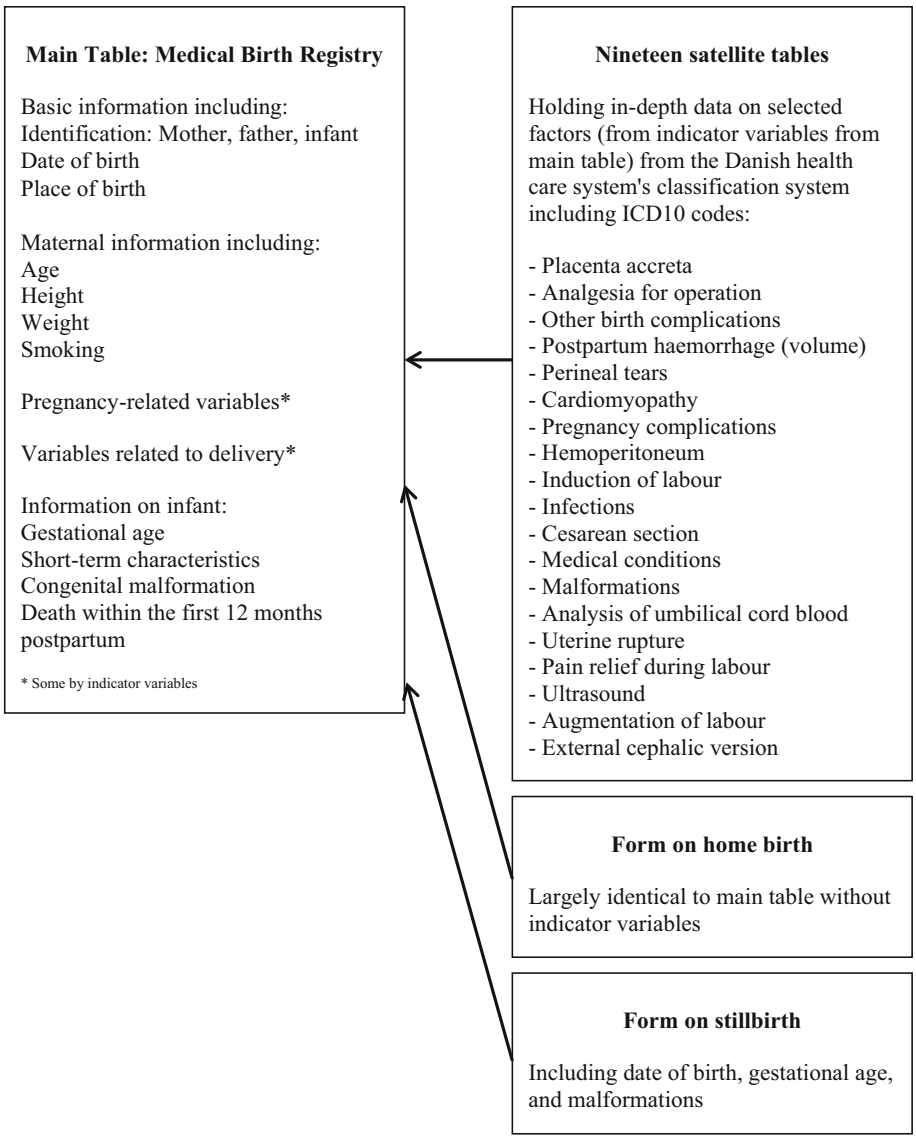

Fig. 2 Structure and main content of the Danish Medical Birth Register since 1997

Table 1 Variable names and English translation of the most used variables in the Danish Medical Birth Register

Danish variable name	English translation
Basic	
pk_mfr	Encrypted administrative variable coupling of data sets
cpr_barn	Encrypted person identifier—child
cpr_moder	Encrypted person identifier—mother
cpr_fader	Encrypted person identifier—father
Mother	
Alder_moder	Age—mother (at date of delivery)
Bmi_moder	BMI—mother (prior to conception)
Paritet	Parity, number of completed pregnancies including stillbirths at the end of the current delivery
Rygerstatus_moder	Smoking status—mother (in pregnancy)
Delivery	
Epiduralblokade	Epidural (SKS procedures)
Episiotomi	Episiotomy (SKS code, 0 or 1 = episiotomy)
Foedested	Place of birth (SKS code)
Foedselsdato	Date of birth
Markoer_andre_foedselskomplikati	Indicator—other pregnancy complications (ICD-10: O60 and O75)
Markoer_b_misdannelse	Indicator—malformation (DQ00–DQ99)
Markoer_kejsersnit	Indicator—Caesarean section (procedure code KMCA)
Newborn	
Apgarscore_efter5minutter	Apgar score after 5 min
Flerfoldsgraviditet	Multiple pregnancy diagnosis (ICD-10 code)
Doedsdato_barn	Date of child's death
Gestationsalder_dage	Gestational age (days)
Koen_barn	Child sex
Laengde_barn	Length—child (cm)
Levende_eller_doedfoedt	Alive or stillborn (before or during delivery)
Vaegt_barn	Weight—child (g)

BMI Body Mass Index, *SKS* Sygehusvæsnets Klassifikationssystem (Health Care System's Classification System), *ICD*-10 International Classification of Diseases codes (version 10), *cm* centimeters

umbilical cord, or movements) is defined as live born, and thus included in the MBR.

Volume and characteristics

Aggregate information from the MBR is publicly accessible and can be found on www.esundhed.dk (accessed September 20 2017).

From January 1st 1997 to December 31st 2016, the population cohort includes data on 1,276,323 newborn infants from 1,249,822 pregnancies. Table 3 informs on number of infants born in Denmark in selected years. The number of newborn infants per year was highest in the late 1990s dropping to a stable approximately 65.000 per year during 2001–2010. From 2010 to 2013, the number of newborn infants dropped dramatically from 64,416 to 56,885. Since then, the number of newborns has increased to 62,760 in 2016.

In Table 4, characteristics of the newborn infants in selected years are presented. During these years, the distribution of birth weight, birth length, and Apgar score has been fairly consistent and percentage of missing data is constantly low, ranging from < 1 to 4%.

Information on labour and delivery is presented in Table 5 including information on missing data. During the last 15 years, the rate of interventions has increased for induction of labour (from 11% in 2000 to 23% in 2016), augmentation (stimulation) of labour (from 12% in 2001 to 18% in 2016), and caesarean section (from 14% in 1997 to 20% in 2016). Data is complete for these variables. From 1997 to 2000, underestimation of prevalence of induction and augmentation of labour is likely due to the phasing-in period of these variables. Missing data on gestational age at

Table 2 Variables added to or changed in the Danish Medical Birth Register since 1997

Variable content	New/changed year[a]
Amniotic fluid infusion	1998/–
Epidural analgesia	2000/–
CPAP	2001/–
Respiratory therapy in neonatal unit	2001/–
Caesarean section on maternal request[b]	–/2002
Home visits	2003/–
Maternal height	2003/–
Maternal weight	2003/–
Maternal body mass index	2003/–
Definition of a still born infant[c]	–/2004
Indicator variables	
Analysis of umbilical cord blood[d]	1998/2004
Pain relief	1999/–
Ultrasound scan	1999/–
Labour stimulation[b]	–/1999
Analgesia for surgery	2000/–
Postpartum haemorrhage	2009/–
Blood loss volume[d]	2009/–

CPAP continuous positive airway pressure therapy

[a]The start year indicated is subject to a slight uncertainty due to a phase-in period

[b]Some information on these variables exists prior to year specified, but data are changed to be more specific

[c]Delivery of a foetus with no sign of life after gestational week 22 + 0. Before 2004, a dead foetus delivered before gestational week 28 + 0 was considered a miscarriage and registered in the National Patient register but not in the Medical Birth Register

[d]Specific variables in the satellite tables are included at a later time

delivery decreased from 8% in 1997 to 1% in 2001 and has remained constant at that level since then.

Regarding maternal characteristics, the percentage of women aged 35 years or more at the time of delivery has increased from 13 to 21%. The percentage of primipara women was 42% in 1997 increasing slightly to 48% in 2016. Smoking status in the first trimester and pre-pregnancy maternal BMI were not registered until late 1997 and 2003, respectively, but reporting of data for both variables increased rapidly and stabilised with completeness reaching > 95% after a few years. The percentage of women smoking during pregnancy has decreased continuously since the registration started from 16 to 6% in 2016. Maternal BMI ≥ 25 remained fairly constant from 30% in 2005 to 33% in 2016.

Validity

Data in the MBR is secondary data collected for administrative purposes and researchers should as always be aware of coding practices. Validation of data is a constant need, as both coding practice and clinical practice change over time. Systematic validation is time- and resource demanding and has only been performed once in the MBR. A validation of the MBR, using medical records as the golden standard, was performed on all data registered in the MBR during 1 week in January 2001 [13]. Findings showed that most well-defined surgical interventions, procedures, and diagnoses were valid, whereas the sensitivity of registered pain relief was lower. Important for researchers, the more detailed sub-classification of diagnoses, the less valid the information becomes. Chapters and main diagnoses are usually of high validity, whereas subgroups (described by fifth and sixth character in the ICD-10 codes) might be less valid [13].

A few validation studies on specific variables related to the MBR (either from MBR or the NPR) have been published since 1997 [14–17]. These studies have validated diagnoses based on ICD-10 codes of gestational diabetes mellitus, second trimester spontaneous deliveries, uterine ruptures, and preeclampsia-related diagnoses in various cohorts of women with medical records as golden standard.

Table 3 Number of births and deliveries included in the Danish Medical Birth Register for selected years since 1997

	1997	2001	2006	2011	2016
	n (%)				
Number of deliveries	66,917 (100)	64,548 (100)	64,361 (100)	58,745 (100)	61,687 (100)
Singletons	65,668 (98)	63,131 (98)	62,918 (98)	57,475 (98)	60,623 (98)
Multiples	1249 (2)	1417 (2)	1443 (2)	1270 (2)	1064 (2)
Number of infants	68,218 (100)	65,999 (100)	65,817 (100)	60,034 (100)	62,757 (100)
Still births[a]	378 (1)	306 (< 1)	307 (< 1)	259 (< 1)	240 (< 1)
Live births	67,840 (99)	65,693 (> 99)	65,510 (> 99)	59,775 (> 99)	62,517 (> 99)

n number

[a]Still birth (Until 31th March 2004): delivery of a dead foetus after 28th completed week of pregnancy. From 1th April 2004: delivery of a dead foetus after 22nd completed week of pregnancy

Table 4 Characteristics of newborn infants in the Danish Medical Birth Register

	1997	2001	2006	2011	2016
			n (%)		
Number of infants	68,288 (100)	66,056 (100)	65,772 (100)	59,899 (100)	62,318 (100)
Birth weight					
< 2500 g	3487 (5)	3720 (6)	3370 (5)	3329 (6)	3102 (5)
2500–4500 g	60,871 (91)	59,374 (90)	59,183 (90)	53,878 (90)	56,016 (90)
> 4500 g	2555 (4)	2455 (4)	2231 (3)	1605 (3)	1659 (3)
Missing	1375 (< 1)	507 (< 1)	988 (2)	1087 (2)	1541 (2)
Birth length					
< 50 cm	9852 (14)	9502 (14)	9666 (15)	10,106 (17)	10,699 (17)
50–54 cm	47,928 (70)	46,370 (70)	46,974 (71)	42,455 (71)	44,152 (71)
55 + cm	9126 (13)	9668 (15)	7906 (12)	6442 (11)	5926 (10)
Missing	1382 (2)	516 (< 1)	1226 (2)	896 (2)	1541 (2)
Apgar score after 5 min					
0–3	166 (< 1)	144 (< 1)	165 (< 1)	207 (< 1)	184 (< 1)
4–6	421 (< 1)	379 (< 1)	307 (< 1)	346 (< 1)	304 (< 1)
7–10	64,984 (95)	64,506 (98)	64,097 (97)	57,999 (97)	59,886 (97)
Missing	2717 (4)	1027 (2)	1203 (2)	1347 (3)	1944 (3)

n numbers

In short, the more severe the condition, the higher validity of the coding in the registers was found and less severe complication was under-ascertained. Excepted was a severe and rare obstetric complication such as uterus rupture after planned Caesarean sections. For this diagnosis both the sensitivity and the positive predictive value of the diagnosis was found to be inadequate during a period between 1997 and 2007, and had values of 51% (95% CI 48–55%) and 63% (95% CI 59–67%), respectively [16]. Consequently, after this study, coding of uterus rupture in the MBR changed and guidelines on coding were elaborated. It is still unknown if these initiatives have increased the validity. A Nordic prospective study collecting data from clinicians and birth registers in 2009-2012 on serious rare obstetric complications such as uterine rupture and excessive postpartum bleeding hopefully have increased familiarity with coding and subsequently improved data validity in the Nordic Birth registers [18]. Although depending on time and specific variables/areas of interest, these studies provide some indication of which variables are reliable, while generally emphasizing that caution is needed when using the MBR.

The above-mentioned studies have focused on diagnoses, which may have been suspected to be of poor validity. Importantly, however, the basic information such as identification of mother for linkage, parental age, parity, gestational age, and date of birth as well as data on the newborn infant such as sex, birth weight, Apgar score at 5 min, and vital status are virtually complete and are of very high validity. Some of these are drawn directly from the Civil Registration System, which hold very high validity, and others are mandatory to report when the newborn is registered after delivery [10, 19].

Data resource use

The MBR is used extensively, both alone [20, 21] and in combination with other registers such as the NPR [22–24], the National Prescription Registry [25], the Integrated Database for Labour Market Research [26], and the Danish Register of Causes of Death [27]. One of the largest birth cohorts in the world, the Danish National Birth Cohort [28], is based on a combination of data the from MBR and information from interviews with the mothers along with blood samples collected during and after pregnancy. Continuous follow-up by register-based information on mothers and offspring and intermittent interviews and questionnaires to groups of individuals from the large cohort provide data for numerous studies examining exposures and outcomes of both mothers and offspring [26, 29–31]. A Danish Pregnancy Planning cohort including almost 6000 women is also linked to the MBR, as well as other registers [32–35].

The MBR is a central register in Denmark and feeds data to several registers/databases such as the Danish National Quality Database for Births, the Danish Twin Registry, the Danish Fertility Database, the In Vitro Fertilisation Register, and the Danish Fetal Medicine Database [20, 36–39]. Further, it forms the base for public access to aggregated data on Danish births available at www.esundhed.dk.

Table 5 Maternal characteristics and mode of delivery in the Danish Medical Birth Register

	1997	2001	2006	2011	2016
			n (%)		
Number of deliveries	66,917 (100)	64,548 (100)	64,361 (100)	58,745 (100)	61,687 (100)
Onset of delivery					
Induced	1984 (3)	7479 (12)	9634 (15)	13,809 (24)	13,990 (23)
Interventions					
Instrumental delivery	5587 (8)	5328 (8)	5211 (8)	4491 (8)	4043 (7)
Oxytocin augmentation	–	7503 (12)	12,855 (20)	13,282 (23)	11,189 (18)
Epidural analgesia	–	–	1729 (3)	8533 (15)	9737 (16)
Caesarean (section)					
Emergency section (pre-labour)	–	10 (< 1)	1717 (3)	1626 (3)	1763 (3)
Elective section	2490 (4)	3439 (5)	5423 (8)	5334 (9)	5105 (8)
During labour					
Previous planned	317 (< 1)	826 (1)	611 (1)	512 (1)	492 (1)
Emergency	1413 (2)	3871 (6)	5376 (8)	4694 (8)	4593 (7)
Unspecified	4422 (7)	2788 (4)	250 (< 1)	155 (< 1)	69 (< 1)
Gestational age (full weeks)					
< 37	3356 (5)	4081 (6)	4004 (6)	3476 (6)	3536 (6)
37–40	40,710 (61)	42,734 (66)	44,888 (70)	39,616 (67)	41,511 (67)
41 +	17,164 (26)	17,316 (27)	14,949 (23)	14,821 (25)	15,703 (25)
Missing	5687 (8)	417 (1)	520 (1)	832 (1)	937 (2)
Mothers age at delivery (years)					
< 25	11,405 (17)	9210 (14)	7301 (11)	7438 (13)	7470 (12)
25–29	24,698 (37)	23,721 (37)	20,757 (32)	17,686 (30)	20,708 (34)
30–34	22,326 (33)	21,483 (33)	24,622 (38)	21,068 (36)	20,723 (34)
35 +	8488 (13)	10,134 (16)	11,681 (18)	12,553 (21)	12,786 (21)
Mothers BMI[a] at start of pregnancy (units)					
< 18.5 (Underweight)	–	–	2437 (4)	2294 (4)	2633 (4)
18.5–24 (Normal weight)	–	–	37,260 (58)	34,150 (58)	36,264 (59)
25 + (Overweight)	–	–	18,826 (29)	19,446 (33)	20,160 (33)
Missing	66,917 (100)	64,548 (100)	5838 (9)	2855 (5)	2630 (4)
Parity					
Parity ≥ 1	37,722 (56)	35,833 (56)	35,042 (54)	30,957 (53)	31,151 (50)
Parity 0	28,207 (42)	27,160 (42)	27,925 (43)	25,922 (44)	29,563 (48)
Missing	988 (1)	1555 (2)	1394 (2)	1866 (3)	973 (2)
Smoking[b]					
Stopped during pregnancy	< 5 (0)	1280 (2)	1492 (2)	1546 (3)	2011 (3)
Smoker	6 (0)	11,780 (18)	8179 (13)	5247 (9)	3987 (6)
Non-smoker	716 (1)	49,258 (76)	52,638 (82)	50,187 (85)	53,257 (86)
Missing	66,194 (99)	2230 (3)	2052 (3)	1765 (3)	2432 (4)

n numbers, *BMI* Body Mass Index (weight (kg)/height $(m)^2$)

[a]Recording started in late 2003

[b]Recording started in late 1997

Strengths and weaknesses

The main strength of the MBR is the nationwide coverage of all births in Denmark [5].

Through linkage to other health and social registers, researchers can study reproductive conditions and outcomes in a nationwide cohort within a relatively stable, homogenous population and with a long term follow-up

[40]. Due to the Danish Civil Registration System, virtually complete follow-up on all mothers and offspring is possible and associated with very limited risk of selection bias. Inclusion of information on maternal smoking and BMI is also a strength while both are important variables in many studies on reproductive health as either exposures or covariates and are often missing in other registers. The content of MBR does not change after validation by medical records and what has been reported from the clinicians stays in the register, but the MBR is a live register in the sense that changes in registration due to earlier errors in the algorithm of data transfer from the Danish National Patient register to the MBR are added retrospectively. Further, any systematic errors found in the specification of the MBR are corrected. The latest update is thus always considered to be the most valid and this change in validity over time should be considered in studies using data from different time periods.

Some limitations should be mentioned. Although the MBR is a nationwide register, studies on very rare diseases or obstetric complications may be difficult to perform due to the small Danish population (5.7 million), and international collaboration is important [41]. Researchers should be careful when using variables that have changed over time such as definition of stillbirth. The inclusion of dead foetuses born before 28 + 0 gestational weeks as stillborns rather than miscarriages (which is not included in the MBR) gives rise to a to a sudden increase in the occurrence of stillbirths after 2004, which is solely caused by this change in registration practice. The MBR is an administrative register, and the Danish Health Data Authority does not clean or manage the data after entry, e.g. by removing or correcting unrealistic outliers on birth weight or gestational age at birth. Data cleaning and management performed by individual researchers after retrieval of data sets may lead to dissimilarities between initially identical datasets. Any errors in data found by researchers are not corrected in the main register. Although the register holds information on possible lifestyle factors such as BMI and smoking, data on alcohol intake is not included. Finally, the register does not include data on Danish maternities or births when delivery occurs abroad.

Data access

The Danish Health Data Authority is responsible for the management of the MBR. Individual-level consent is not needed before using the data for research purposes. Researchers with a project of public interest and working under an institutional authorisation can gain access to data through Statistics Denmark or the Danish Health Data Authority under the Act of Processing of Personal Data [42, 43]. Prior to application, the Danish Data Protection Agency should accept the project and data handling [42].

Data is made available via the Danish Health Data Authority with as little as 1–2 months delay, whereas the copy of the MBR available at Statistics Denmark is usually only updated once a year, with some delay. Data from registers other than health registers such as socioeconomic-, income-, and education registers are only available through Statistics Denmark and cannot be used in studies analysed elsewhere. Both Statistics Denmark and the Danish Health Data Authority offer access to MBR for well-defined projects on secure servers with double log-on procedures. Within the respective servers, the unique CPR number enables linkage to other registers or data collected by the researcher. The linkage is performed by the respective institution which subsequently grants access to the data in pseudo-anonymised form. The servers feature common analytical tools such as R, SPSS, SAS, and Stata software.

Conclusion

The MBR is a valuable resource for reproductive epidemiological research with information on all births in Denmark since 1973. Due to the Civil Registration System, it is possible to unambiguously follow all newborn infants in Denmark from birth and study associations between reproductive conditions and subsequent health, and even between generations. As some variables holds varying validity, caution is needed when using the MBR.

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Compliance with Ethical Standards

Conflict of interest The authors declare no conflicts of interest.

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