2.2.2 Coding Instructions for the variables

Baby and Mother (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
1	CENTRE	CENTRE NUMBER	Code allocated by Central Registry
2	NUMLOC	LOCAL ID Each case has a unique identification. This number is a maximum of 11 characters long, consisting of numbers, letters or both. ID numbers should not repeat themselves in different years.	Up to 11 digits
3	BIRTH_DATE	DATE OF BIRTH Please enter dates in one of the following format: dd/mm/yyyy, yyyy/mm/dd, yyyy/mm/xx, yyyy/xx/xx. Old formats are also accepted: ddmmyy, 99mmyy and 9999yy. Please make sure to choose one format and stick to it.	Day, month, year xx = Not known for day and month **DO NOT TRANSMIT RECORDS IF YEAR OF BIRTH IS NOT KNOWN**
4	SEX	SEX Indicate chromosomal sex, if known, in case of ambiguous genitalia code malformations in variables 32-47. Indicate indeterminate sex in case of ambiguous genitalia with unknown or abnormal sex chromosome complement. If sex could not be determined at autopsy due to maceration, very small fetus, or other problems, indicate as “not known”.	1 = Male 2 = Female 3 = Indeterminate 9 = Not known
5	NBRBABY	NUMBER OF BABIES/FETUSES DELIVERED Fill out a separate form for each malformed baby/fetus in a multiple set. Only one form is to be completed for conjoined twins (Siamese). The code is “2” for a conjoined twin unless another baby was delivered at the same time (code “3”). Conjoined twins have a specific ICD/BPA code, to be coded under “MALFO1” (variable 32). Give full description of the type of conjoined twinning in MALFO1 text field (variable 33). Any other anomalies are coded in variables 32-47. Notes. If code 8 is used, please specify in variable sp_twin the gestational age at which last known to be a multiple pregnancy and/or first known to be a singleton. The purpose of this coding system is to allow us to distinguish malformed cases which would have civil registration as singleton births from malformed cases which would have civil registration as multiple births. Please specify the sex and outcome (live, still) of the malformed/non-malformed co-twin and zygosity.	1 = Singleton 2 = Twins 3 = Triplets 4 = Quadruplets 5 = Quintuplets 6 = Sextuplets or more 7 = Multiple birth, number of babies not known 8 = Singleton at time of delivery/termination, but known to have been a multiple pregnancy at an earlier stage in pregnancy 9 = Not known

Baby and Mother (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
6	SP_TWIN	SPECIFY TWIN TYPE OF BIRTH (malformed and non-malformed), like or unlike sex, zygosity	Free text
7	NBRMALF	NUMBER OF MALFORMED IN MULTIPLE SET To be completed for multiple delivery only. Remember to give local ID of co-twin in SIB1 field (variable 84) if more than one malformed.	1 = One 2 = Two 3 = Three 4 = Four 5 = Five 6 = Six or more 9 = Not known
8	TYPE	TYPE OF BIRTH Birth with the type of birth not known should be transmitted to EUROCAT, but will be excluded from routine EUROCAT analysis. EUROCAT includes all live births, fetal deaths with gestational age (GA) ≥20 weeks, and terminations of pregnancy (at any gestational age) after prenatal diagnosis of malformation (TOPFA). Fetal deaths with gestational age (GA) < 20 weeks (code = 3) may be reported to EUROCAT but will not be included in prevalence data. All cases MUST have been confirmed as having a MAJOR congenital anomaly (see exclusion list, chapter 3.2). The distinction between stillbirth and spontaneous abortion should follow the definitions in use in your country (to be specified in your Registry Description). There is usually a lower gestational age limit or birthweight limit for stillbirths. This varies from country to country. Below this limit, fetal deaths are called spontaneous abortions. Terminations of pregnancy refer to cases where a prenatal diagnosis was made of malformation in a live fetus and the pregnancy was then terminated. If the fetus died spontaneously *in utero* either before or after prenatal diagnosis of malformation then it should be coded as spontaneous abortion or stillbirth, not as termination of pregnancy. If termination was performed for other reasons than malformation, the case should not be transmitted to Central Registry. This means that early terminations where there was no suspicion of malformation before termination should be excluded from the case files. Stillbirths or perinatal deaths resulting from termination of pregnancy following prenatal diagnosis must be coded as terminations (value = 4), irrespective of civil registration status. For a non-natural fetal reduction in a multiple pregnancy where one fetus is malformed, code 4 (in that case gestlength = gestational age at reduction; date of birth =	1 = Live birth 2 = Stillbirth 3 = Spontaneous abortion 4 = TOPFA 9 = Not known

Baby and Mother (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
		date of reduction; and code carefully all multiple birth variables).	
9	CIVREG	CIVIL REGISTRATION STATUS Live births and stillbirths are civilly registered leading to either birth or stillbirth certificates and appear in official birth statistics for your region. Code here whether this case fulfilled the conditions for live or stillbirth registration in your country.	1 = Live birth 2 = Stillbirth 3 = No civil registration 9 = Not known
10	WEIGHT	BIRTH WEIGHT Give weight in grams.	9999 = Not known (Do not use 99 or 999 for "Not Known" as this will be considered the birth weight).
11	GESTLENGTH	LENGTH OF GESTATION IN COMPLETED WEEKS Give best estimate based on last menstrual period (LMP) and/or ultrasound determination. If the case is the result of fetal reduction give GA at feticide.	99 = Not known
12	SURVIVAL	SURVIVAL BEYOND ONE WEEK OF AGE Yes = Child known to be alive after one week. No = Child known to have died before or during the first week (including stillbirths and abortions). Alive at discharge <1 week refers to cases that are alive at discharge from maternity units before one week of age. Please specify in your Registry Description the day when discharge from maternity units usually takes place. If survival at one week is unknown, but survival at discharge from maternity unit less than one week is known, use the latter. The definition of the first week of life varies between countries. Follow your country's perinatal mortality definition and specify this in your Registry Description. Not known = Not known if a child has died during first week.	1 = Yes 2 = No 3 = Alive at discharge <1 week 9 = Not known
13	DEATH_DATE	DATE OF DEATH **For live births only.** Please enter dates in one of the following format: dd/mm/yyyy, yyyy/mm/dd, yyyy/mm/xx, yyyy/xx/xx and xxxx/xx/xx. Old formats are also accepted: ddmmyy, 99mmyy, 9999yy, 999944, 222222 and 333333. Please make sure to choose one format and stick to it.	Day, month, year xx = Died, not known day or month xxxx =Died, not known year 2222/22/22 = Known to be alive at 1 year 3333/33/33 = Not known if alive or dead at 1 year

Baby and Mother (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
14	DATEMO	DATE OF BIRTH OF MOTHER Give as much information as is known e. g. Feb 1963 = 1963/02/xx, 1963 = 1963/xx/xx. Please enter dates as dd/mm/yyyy, yyyy/mm/dd, yyyy/mm/xx, yyyy/xx/xx and xxxx/xx/xx. Old formats are also accepted: ddmmyy, 99mmyy, 9999yy and 999944. Please make sure to choose one format and stick to it. This variable can be used to calculate maternal age at Expected Date of Delivery for preterm deliveries and terminations.	Day, month, year xx = Not known day or month xxxx = Not known year
15	AGEMO	AGE OF THE MOTHER AT DELIVERY In completed years at the time of delivery. If only the year of birth is available, assume that the mother was born on 30 June.	99 = Not known
16	BMI	MATERNAL BODY MASS INDEX Enter BMI (rounded to one decimal place). The DMS will also allow entry of maternal height (in centimetres) and weight (in kilograms) and calculate BMI automatically. Values measured at first antenatal visit are preferred, but pre-pregnancy self-reported values may be given. If the mother is known to be obese, enter code for obesity E660 in maternal illness before pregnancy (variable 60). BMI was a new variable in Guide 1.4. If any registry has information on maternal BMI for previous years, EUROCAT is interested in collecting this information from 2005 onwards.	Rounded to one decimal place Expected range 15 – 50 96 = exact BMI not known but BMI < 18.5 97 = exact BMI not known but 18.5 to <30 98 = exact BMI not known but >=30 99 = Not known
17	RESIDMO	MOTHER'S RESIDENCE CODE Use local code for locality of residence at time of delivery.	Local code (up to 10 digits)
18	TOTPREG	TOTAL NUMBER OF PREVIOUS PREGNANCIES NOTE – The current reported pregnancy is NOT included. Include all previous abortions whether spontaneous or induced. Multiple pregnancies count as 1 in the total.	00 = None 01 = One 02 = Two 03 = Three, etc. 20 = Twenty or more 99 = Not known

Diagnosis (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
19	WHENDISC	WHEN DISCOVERED When the baby was first suspected of having a congenital anomaly. For prenatal diagnosis: when a major congenital anomaly was first suspected (EXCLUDING soft markers except if nuchal translucency indicates a very high risk followed by confirmation of diagnosis at delivery/termination). If a prenatal diagnosis is made when a fetus is dead code 1 (for stillbirths) or 7 (for spontaneous abortions). For live births: when the first suspicion of an anomaly was at death OR at *post mort*em, when discovered is the age at death (e.g. at birth, < 1 week, 1-4 weeks etc.). For stillbirths: when the first suspicion of an anomaly was at birth OR at *post mortem*, when discovered is at birth (e.g. Code = 1). All cases MUST have been confirmed as having a MAJOR congenital anomaly (see exclusion list, chapter 3.2). EUROCAT accepts a positive NIPT for trisomy 13, 18 and 21 without a full karyotype. Please also complete variables 12 "SURVIVAL", 13 "DEATH-DATE", 20 "CONDISC" and 28 "PM".	1 = At birth 2 = Less than 1 week 3 = 1-4 weeks 4 = 1-12 months 5 = Over 12 months 6 = Prenatal diagnosis in live fetus 7 = At abortion (spontaneous) 9 = Not known 10 = Postnatal diagnosis, age not known
20	CONDISC	CONDITION AT DISCOVERY Condition of fetus or baby when malformation was first suspected.	1 = Alive 2 = Dead 9 = Not known
21	AGEDISC	IF PRENATALLY DIAGNOSED, GESTATIONAL AGE AT DISCOVERY IN COMPLETED WEEKS GA as defined in variable GESTLENGTH. Gestational age at which the fetus was first suspected to be malformed (EXCLUDING soft markers). Indicate time of examination rather than time when the result was known. If no prenatal diagnosis please leave blank.	99 = Not known
22	FIRSTPRE	FIRST POSITIVE PRENATAL TEST This refers to the first prenatal test whether screening procedure or diagnostic test which indicated a possible congenital anomaly or need for further tests. For code 7 = other specified test, give information in the text field (variable 23). If test performed and result negative, then the "When discovered" variable cannot be coded 6 (prenatal diagnosis). This field is to record what DID happen, not any possible plans or intentions. Ultrasound < 14 weeks means only	1 = Ultrasound at GA < 14 weeks 2 = Ultrasound at GA 14-21 weeks 3 = Ultrasound at GA ≥ 22 weeks 4 = Ultrasound GA not known 5 = Serum/ combined screening 6 = Chorion villus sampling or amniocentesis

Diagnosis (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
		ultrasound performed which may include a nuchal measurement. The serum/combined screening must involve a biochemical test	7 = Other test positive 8 = Test(s) performed, result negative 9 = Not known 10 = No test performed 11 = Fetal karyotype on maternal blood
23	SP_FIRSTPRE	SPECIFY "OTHER" FIRST PRENATAL TEST If FIRSTPRE = 7, specify which positive prenatal test	Free text
24	KARYO	KARYOTYPE OF INFANT/FETUS Specify the result in variable 25. Array results count as a karyotype test. Report only clearly pathogenic variants and if uncertain, include only copy number variants (CNVs) (duplications or deletions) larger than 1 MB. Only report cases with de novo CNVs unless the parent in familial cases also has clinical manifestations of the condition (dysmorphic features or congenital anomalies). (Coding Committee 2015) If performed and results known, please specify (according to the latest ISCN edition). "Probe test performed" refers to FISH, PCR, NIPT or other analyses restricted to specific chromosomal regions. "Failed" refers to a technical failure where a repeat examination could not be done and the karyotype is therefore unknown.	1 = Performed, result known 2 = Performed, results not known 3 = Not performed 4 = Probe test performed 8 = Failed 9 = Not known
25	SP_KARYO	SPECIFY KARYOTYPE OR CHROMOSOMAL MICROARRAY EXAMPLES: 47,XY,+21 46,XX,del(2)(p13p23)*mat* ***Description:*** *An interstitial deletion resulting from mal-segregation of a maternal insertion* 46,XY,der(5)ins(5;2)(q31;p23p13)mat ***Description*** *: A derivative chromosome 5 resulting from mal-segregation of a maternal insertion from chromosome 2* arr(1–22)×3,(X)×2,(Y)×1 ***Description:*** *Microarray analysis shows triploidy 69,XXY* arr(8)×3,(21)×3 ***Description****: Microarray analysis shows a single copy gain of chromosomes 8 and 21.* 46,XY.rsa(13,18,21)×2,(X,Y)×*1* ***Description:*** *normal chromosomes, only chromosome 13,18,21, X and Y investigated*	Free text

Diagnosis (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
		rsa 22q11.2('kit name')×1 ***Description**: microdeletion 22q.11.2 diagnosed by multiple ligation probe amplification method (MLPA)*	
26	GENTEST	GENETIC TEST For syndromes and single gene disorders, a genetic test may have confirmed the clinical diagnosis either prenatally or postnatally. Please complete for these cases. Karyotype should still be completed as per variables 24 & 25 If any registry has this information for previous cases, EUROCAT is interested in collecting this information from 2005 onwards If the test is performed but the result not yet known, please wait for the result before reporting.	1 = specific genetic test positive 2 = specific genetic test negative 3 = Specific genetic test not Performed 9 = Not Known if genetic test is performed or result not known
27	SP_GENTEST	SPECIFY TYPE OF GENETIC TEST Give method used and the result of the test (type of mutation and which gene) Examples: Single gene analysis, exome sequencing, gene panel analysis, whole genome sequencing.	Free text
28	PM	*POST MORTEM* EXAMINATION If performed, record the malformation(s) discovered in the "malformation" section in the form. If other findings, record in the "comments" space (variable 95). "Results known" means that the autopsy record has been reviewed by the registry. "Results not known" means that the autopsy record was not available to the registry. "Macerated fetus" means that although a *post mortem* was performed, maceration of the fetus prevented a full protocol from being followed.	1 = Performed, results known 2 = Performed, results not known 3 = Not performed 4 = Macerated fetus 9 = Not known
29	SURGERY	FIRST SURGICAL PROCEDURE FOR MALFORMATION (PERFORMED OR EXPECTED) **Complete for all live births and fetal deaths (only if there was prenatal surgery).** The variable surgery does not include insertions of catheters. Performed (or expected) means that this case has already, or will at the appropriate age, have surgery for one or more of the listed malformations. "No surgery required" means that this case does not have a severe enough malformation, or that the malformation is not correctable by surgery. "Too severe for surgery" means that there has been an active decision to withhold surgery due to low chances of survival or very poor prognosis.	1 = Performed (or expected) in the first year of life 2 = Performed (or expected) after the first year of life 3 = Prenatal surgery 4 = No surgery required 5= Too severe for surgery 6 = Died before surgery

Diagnosis (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
			9 = Not known
30	SYNDROME	SYNDROME OR ASSOCIATION All cases MUST have been confirmed as having a MAJOR congenital anomaly (see exclusion list, chapter 3.2). Use this variable for genetic syndromes, skeletal dysplasias, hereditary skin disorders teratogenic syndromes, associations, microdeletions and chromosomal anomalies. Refer to EUROCAT Guide on syndromes. Give the name of syndrome or association in text variable 31. All the anomalies observed by the local clinician should be coded in the remaining boxes for malformations. If not a recognised syndrome or association, leave blank. When 2 syndromes are present in the same subject, code the more important one in the syndrome variables 30 and 31, and include the other one in variables 32 and 33 MALFO1. Ensure karyotype information is given in variables 24 and 25 and that information on genetic tests are given in variable 26 and 27. Mention in variable 28 if the autopsy report has been reviewed, where appropriate. Local registries are advised to keep photographs and x-ray images of all syndrome cases if possible, as the diagnosis might be established on the basis of specific facial dysmorphism.	ICD 10 First 4 digits are ICD10 5th digit = BPA supplement or leave blank
31	SP_SYNDROME	SPECIFY SYNDROME Written text description of the ICD10 code in variable 30.	
32	MALFO1	MALFORMATION All cases MUST have been confirmed as having a MAJOR congenital anomaly (see exclusion list, chapter 3.2). A baby/fetus with ONLY minor anomalies (see exclusion list, chapter 3.2) should not be transmitted to Central Registry. This rule does not concern established syndromes (e.g. Down, Beckwith Wiedemann or Prader Willi syndrome without a major congenital anomaly are to be submitted). When a major anomaly is present, code both major and minor anomalies. In the case of conjoined twins, give a full description in text in variable 33. Up to 8 malformations can be coded – if more than 8 are present, specify additional anomalies in the text variable for the 8th anomaly (text variable 47 SP_MALFO8). Include in the 8 specified codes the most important ones, or those tabulated in EUROCAT Reports.	ICD 10 First 4 digits are ICD 5th digit = BPA classification OR leave blank

Diagnosis (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
		Give written description of the malformations available in malformation text variables 33, 35, 37, 39, 41, 43, 45 and 47.	
33	SP_MALF01	SPECIFY MALFORMATION	Free text
34	MALF02	AS MALF01	As MALF01
35	SP_MALF02	SPECIFY MALFORMATION	Free text
36	MALF03	AS MALF01	As MALF01
37	SP_MALF03	SPECIFY MALFORMATION	Free text
38	MALF04	AS MALF01	As MALF01
39	SP_MALF04	SPECIFY MALFORMATION	Free text
40	MALF05	AS MALF01	As MALF01
41	SP_MALF05	SPECIFY MALFORMATION	Free text
42	MALF06	AS MALF01	As MALF01
43	SP_MALF06	SPECIFY MALFORMATION	Free text
44	MALF07	AS MALF01	As MALF01
45	SP_MALF07	SPECIFY MALFORMATION	Free text
46	MALF08	AS MALF01	As MALF01
47	SP_MALF08	SPECIFY MALFORMATION	Free text
48	PRESYN	PRENATAL DIAGNOSIS FOR SYNDROME When each anomaly was first diagnosed. The basis for this variable is to record whether the prenatal findings strongly suggest the postnatal diagnosis. This variable is not designed for fetal medicine specialists to assess the accuracy of their prenatal diagnosis. Thus, the finding of a significant heart anomaly prenatally is considered to be prenatally detected, even if the *exact* anomaly was not correctly diagnosed. *Note: A code "3=partially prenatally diagnosed" was in use until birth year 2021. It has been discontinued but there are cases with the code =3 in the database for some registries.*	1 = Yes, this anomaly was diagnosed prenatally 2 = No, this anomaly was diagnosed postnatally 9 = Not known
49	PREMAL1	PRENATAL DIAGNOSIS FOR MALFORMATION AS PRESYN	AS PRESYN
50	PREMAL2	PRENATAL DIAGNOSIS FOR MALFORMATION AS PRESYN	AS PRESYN
51	PREMAL3	PRENATAL DIAGNOSIS FOR MALFORMATION AS PRESYN	AS PRESYN
52	PREMAL4	PRENATAL DIAGNOSIS FOR MALFORMATION AS PRESYN	AS PRESYN
53	PREMAL5	PRENATAL DIAGNOSIS FOR MALFORMATION AS PRESYN	AS PRESYN
54	PREMAL6	PRENATAL DIAGNOSIS FOR MALFORMATION AS PRESYN	AS PRESYN
55	PREMAL7	PRENATAL DIAGNOSIS FOR MALFORMATION AS PRESYN	AS PRESYN
56	PREMAL8	PRENATAL DIAGNOSIS FOR MALFORMATION AS PRESYN	AS PRESYN
57	OMIM	OMIM / TYPE OF MENDELIAN INHERITANCE To be coded by medical geneticist or after advice from medical geneticist.	

Diagnosis (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
		For reporting OMIM refer to EUROCAT Syndrome Guide. The first digits may be filled in without the rest of the code if the full OMIM code is not known. Full codes can be found on the OMIM website http://www.ncbi.nlm.nih.gov/omim/	
58	ORPHA	This code is to be used for rare diseases including congenital anomalies, chromosomal, teratogenic and genetic syndromes. Use the link and enter the name of the condition. If more than one code/disease appears, select the most specific ORPHAcode. If you do not have specific information about genetic background or phenotype, select the most general ORPHAcode. https://www.orpha.net/consor/cgi-bin/Disease.php?lng=EN	

Exposure (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
59	ASSCONCEPT	ASSISTED CONCEPTION IVF = In vitro fertilization GIFT = Gamete intra fallopian transfer ICSI = Intracytoplasmic sperm injection	0 = No 1 = Induced ovulation only 2 = Artificial insemination 3 = IVF 4 = GIFT 5 = ICSI 6 = Egg donation 8 = Other 9 = Not known 10 = Assisted conception, type unknown
60	OCCUPMO	MOTHER'S OCCUPATION AT TIME OF CONCEPTION Code main occupation at time of conception (or earliest known time in first trimester). Note that the main purpose of the variable relates to potential teratogenic occupational exposures in early pregnancy. Be as precise as possible. Code according to the 2008 International Standard Classification of Occupations (ISCO-08) for births with birth dates from 2013. Code according to the 1988 International Standard Classification of Occupations (ISCO-88) for births with birth dates up to 2012. Links for ISCO classifications: http://www.ilo.org/public/english/bureau/stat/isco/isco08/index.htm Available in many languages. The 4-digit codes give the necessary specificity. They are grouped into the following main groups: 0 = Armed Forces (NB – do not preface your codes with zero UNLESS it is an armed forces occupation. All database systems must accept a leading zero and not drop it). 1 = Managers 2 = Professionals 3 = Technicians and Associate Professionals 4 = Clerical Support Workers 5 = Service and Sales Workers 6 = Skilled agricultural, forestry and fishery workers 7 = Craft and related trades workers 8 = Plant and machine operators, and assemblers 9 = Elementary occupations EUROCAT Supplement: 9991 = Employed (including self-employed), but occupation unknown 9995 = Housewife 9996 = Student 9997 = Unemployed 9999 = Not known whether employed or not	**4 digit** code 9999 = Not known (do NOT use 9, 99 or 999 for not known)

Exposure (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
61	ILLBEF1	ILLNESS BEFORE PREGNANCY 1 Record any maternal illness whether chronic or acute with onset before pregnancy and that may affect fetal development (e. g. childhood cancer, metabolic and endocrine disease, severe congenital anomaly). Code according to ICD10. The codes mentioned below are only examples (non-exhaustive list). If a pregestational diabetic mother has several diseases, indicate the diabetes in variable 63 (MATDIAB) and code the other diseases in variables 61 and 62 (ILLBEF1, ILLBEF2). Historic maternal diseases may be coded using the Z-chapter in ICD10, example Z853 "Personal history of breast cancer". Any additional details may be entered in the general comments section (variable 95). Do not insert the decimal point in the code (e. g. Code E05.0 as E050) Examples, non-exhaustive list: Hyperthyroidism E050 - E059 Hypothyroidism E000 - E039 Diabetes Type 1 E100 - E109 Diabetes Type 2 E110 - E119 Obesity E660 - E669 If maternal BMI ≥ 30 give code for obesity Metabolic disorders E700 - E889 Anorexia /eating disorders F500 -F509 Depression F320 - F339 Epilepsy G400 - G409 Hypertension I100 - I159 Asthma J450 - J459 Chronic alcoholism F102 Drug addict F112 - F122 - F132 - F142 COVID-19 (only report if within 3 months before pregnancy): B342 (previously U071 and U072 were used).	ICD 10 0 = No illness 1 = Yes, but no information available 9 = Not known
62	ILLBEF2	ILLNESS BEFORE PREGNANCY 2 - AS FOR ILLBEF1	
63	MATDIAB	MATERNAL **PRE**GESTATIONAL DIABETES This variable is specifically for **pre**gestational diabetes. Gestational diabetes is dealt with under the 'illness during pregnancy' variable (variable 64) Type 1 diabetes: characterized by hyperglycaemia due to an absolute deficiency of the insulin hormone produced by the pancreas An HbA1c of 48mmol/mol is recommended as the cut-off point for diagnosing diabetes. Type 2 diabetes: characterized by hyperglycaemia due to a defect in insulin secretion An HbA1c of 48mmol/mol is recommended as the cut-off point for diagnosing diabetes.	1 = Yes, type 1 diabetes (IDDM) 2 = Yes, type 2 diabetes (NIDDM) 3 = Yes, type MODY* (all types) 4 = Yes, type not known 5 = No, but impaired glucose intolerance 6 = No pregestational diabetes 9 = Not known

Exposure (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
		*Maturity Onset Diabetes in the Young (MODY) displays an autosomal dominant pattern of inheritance An HbA1c of 48mmol/mol is recommended as the cut-off point for diagnosing diabetes. Impaired Glucose Intolerance is a state of higher than normal blood (or plasma) glucose concentration, but less than the diagnostic cut-off for diabetes. Diagnosed before pregnancy. Diagnosed by fasting plasma glucose from 6.1 - 6.9 mmol/L (WHO criteria)	
64	ILLDUR1	ILLNESS DURING PREGNANCY Record maternal illnesses with chronic or acute onset during the first 20 weeks of pregnancy, including asymptomatic maternal infections. For gestational diabetes include at any point in pregnancy. This variable aims to capture the maternal illnesses that may affect fetal development. For early pregnancy complications use the O chapter in ICD10. For maternal infections, use chapters A and B (4 digits). Fetal infections and associated malformations should be coded under syndrome and malformation 1-8 codes (variable 30-47). Examples (non-exhaustive list): Gestational diabetes O244 - O249 Haemorrhage early pregnancy O200 - O209 Hyperemesis O210 - O219 Fever R502 - R509 Hypertension I100 - I159 Depression F320 - F339 CMV B250 - B259 HIV (AIDS) B200 - B249 Influenza J100 - J119 Mumps B260 - B269 Rubella B060 - B069 Syphilis A530 - A539 Toxoplasmosis B580 - B589 Varicella (Chickenpox) B010 - B019 Viral hepatitis B190 - B199 Zika virus A925 Drug poisoning T360-T509 COVID-19 B342 (previously U071 and U072 were used).	ICD 10 0 = No 1 = Yes, but no information available 9 = Not known
65	ILLDUR2	ILLNESS DURING PREGNANCY AS FOR ILLDUR1	
66	FOLIC_G14	FOLIC ACID SUPPLEMENTATION Recommend to your local maternity hospitals or midwives to collect these data.	1 = Folic acid taken pre- and post-conceptionally

Exposure (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
		Folic acid supplementations include folic acid only tablets, a multivitamin preparation which contains folic acid or contraceptive pills which contain folic acid. If the folic acid dose is high (≥ 4 mg), please add the code B03BB01 in the drugs variable.	2 = Folic acid taken only post-conceptionally 3 = Folic acid not taken 4 = Folic acid taken, timing unknown 9 = Not known if folic acid taken
67	FIRSTTRI	FIRST TRIMESTER MEDICATION "Yes" means that the data sources clearly state that medication was taken in the first trimester. "No" means that the data sources clearly state that no medication was taken in the first trimester. Medications taken in the 2nd or 3rd trimester only should not be added to the DMS. "Medication taken but timing unknown" means that the usual data sources stated that medication was taken but the timing of use was not stated. "Not Known" means that the usual data sources were not found. Only fill in DRUGS1-5 and EXTRADRUGS if you have coded FIRSTTRI = 1 (Yes medication taken) or = 4 (Medication taken, but timing unknown). If you have coded FIRSTTRI = 2 (no medication taken), FIRSTTRI = 9 (unknown), there shouldn't be any ATC codes in any of the DRUGS variables. • Include any medication that was taken by the mother during the first trimester of pregnancy (from the 1st day of the last menstrual period up to the 12th week of gestation). Medication with long elimination half time and taken before conception should be included (e.g. Acitretin, Etretinate, etc.). • Use of folic acid (either as folic acid only tablets or a multivitamin preparation which contains folic acid) should be registered in the folic acid variable, but if the folic acid dose is high (≥ 4 mg), please register FIRSTRI = 1 • Do not include usual vitamins and mineral supplementation, but include unusual intakes of vitamins or minerals (e.g. Vitamin A mega doses). • Only medication taken at physiologic doses should be included. Whilst FIRSTTRI is a new variable introduced in Guide 1.4 (for cases born from 2013 onwards). If any registry has this information for previous cases, EUROCAT is interested in collecting this information from 2005 onwards.	1 = Yes, medication taken in first trimester 2 = No medication taken in first trimester 4 = Medication taken, but timing unknown 9 = Not Known

Exposure (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
		Note: A code "3=undetermined" was in use until birth year 2022. It has been discontinued but there are cases with the code =3 in the database for some registries. It is advised to recode the variable as "9=Not know" when analysing the data.	
68	DRUGS1	DRUGS – 7 DIGITS MAXIMUM Record any drug taken by the mother during the first trimester of pregnancy (from the 1st day of the last menstrual period up to the 12th week of gestation). Drugs with long elimination half time and taken before conception should also be recorded (e.g. Acitretin, Etretinate, etc.). If it is not known in which trimester the drug was taken, and this information cannot be obtained, code it but write in the space for comments that it is not sure whether the drug was taken in the first trimester. Use ATC-coding and use as many digits as possible (from 3 to 7). Website http://www.whocc.no/atcddd/. Do not record usual vitamins and mineral supplementation, but record unusual intakes of vitamins or minerals (e.g. Vitamin A mega doses, folic acid dose ≥ 4 mg). The ATC coding system does not have a code for alternative drugs or herbs. If these are used, give the main code Z. ATC example: N03A: antiepileptic drug N03AF01: carbamazepine Details on the dosage and timing should be given in text variable 69. Do not forget to mention in the appropriate section (disease during or before pregnancy) the indication for drug use. Only drugs taken at physiologic doses to be recorded. If a drug overdose or self-poisoning, this MUST be explained in the drug description.	
69	SP_DRUGS1	SPECIFY DRUG EXPOSURES	Free text
70	DRUGS2	AS FOR DRUGS1 Please give details in text variable 72 SP_DRUGS2.	As for DRUGS1
71	SP_DRUGS2	SPECIFY DRUG EXPOSURES	Free text
72	DRUGS3	AS FOR DRUGS1 Please give details in text variable 74 SP_DRUGS3.	As for DRUGS1
73	SP_DRUGS3	SPECIFY DRUG EXPOSURES	Free text
74	DRUGS4	AS FOR DRUGS1 Please give details in text variable 76 SP_DRUGS3.	As for DRUGS1
75	SP_DRUGS4	SPECIFY DRUG EXPOSURES	Free text
76	DRUGS5	AS FOR DRUGS1	As for DRUGS1

Exposure (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
		Please give details in text variable 78 SP_DRUGS3.	
77	SP_DRUGS5	SPECIFY DRUG EXPOSURES	Free text
78	EXTRA_DRUGS	EXTRA DRUGS This field is only to be used if drug fields 1-5 have already been filled. Record any drug taken by the mother during the first trimester of pregnancy (from the 1st day of the last menstrual period up to the 12th week of gestation). Drugs with long elimination half time and taken before conception should also be recorded (e.g. Acitretin, Etretinate, etc.). If it is not known in which trimester the drug was taken, and this information cannot be obtained, code it but write in the space for comments that it is not sure whether the drug was taken in the first trimester. Use ATC-coding and use as many digits as possible (from 3 to 7). Website http://www.whocc.no/atcddd/. Do not record usual vitamins and mineral supplementation, but record unusual intakes of vitamins or minerals (e.g. Vitamin A mega doses). The ATC coding system does not have a code for alternative drugs or herbs. If these are used, give the main code Z. ATC example: N03A: antiepileptic drug N03AF01: carbamazepine Details on the dosage and timing should be given in the drug description. Do not forget to mention in the appropriate section (disease during or before pregnancy) the indication for drug use. Only drugs taken at physiologic doses to be recorded. If a drug overdose or self-poisoning, this MUST be explained in the drug description. Please enter the ATC code and text description in the following format: <ATC code|text description> If more than one extra drug is to be imported for a single case, then enter the ATC codes in the extra drugs field as follows: <ATC code|text description><ATC code|text description> For example a case with valproate and lamotrigine exposure is entered in the extra_drugs field as: <N03AG01|Valproate><N03AX09|Lamotrigine>	

Exposure (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
79	INF_COV_TEST	COVID-19 INFECTION STATUS OF THE MOTHER (PCR OR ANTIGENIC TEST) Use this variable to record the COVID-19 infection status of the mother obtained from a **PCR or antigenic test only** This field should be completed for all mothers registered since the pandemic outbreak of COVID-19 in 2020. In the event of a mother being tested multiple times record the time of the **first positive PCR or antigenic test in pregnancy.**	0 = No test 1 = Test positive 1st trimester 2 = Test positive 2nd trimester 3 = Test positive 3rd trimester 4 = Test negative 9 = Not known if tested or test result not known
80	IMM_COV_TEST	COVID-19 IMMUNITY STATUS OF THE MOTHER (IGM ANTIBODY TEST) Use this variable to record the COVID-19 immunity status of the mother obtained from **IgM antibody test** This field should be completed for all mothers registered since the pandemic outbreak of COVID-19 in 2020. In the event of a mother being tested multiple times record the time of the **first positive IgM antibody test**	0 = No test 1 = Test positive 1st trimester 2 = Test positive 2nd trimester 3 = Test positive 3rd trimester 4 = Test negative 9 = Not known if tested or test result not known
81	OTH_COV_TEST	COVID-19 STATUS OF THE MOTHER (OTHER TESTS/EXAMS) Use this variable to record the COVID-19 status of the mother obtained from **other tests/exams for diagnosis or confirmation of COVID-19** This field should be completed for all mothers registered since the pandemic outbreak of COVID-19 in 2020. In the event of a mother being tested multiple times record the time of the first positive **test**	0 = No test 1 = Test positive 1st trimester 2 = Test positive 2nd trimester 3 = Test positive 3rd trimester 4 = Test negative 9 = Not known if tested or test result not known
82	SP_OTH_COV_TEST	SPECIFY OTHER COVID-19 TESTS Specify the other tests (**OTH_ COV_TEST**) referred to above.	Free text
83	START_COV	START WEEK OF COVID-19 INFECTION Week of gestation at which the COVID-19 infection is considered to have started.	99 = Not known
84	COV_SEVERITY	SEVERITY OF COVID-19 INFECTION Use this variable to record the severity of COVID-19 infection in the mother.	0 = Asymptomatic 1 = Treated at home 2 = Hospitalised, no ICU 3 = Hospitalised in ICU 9 = Not known

Family History (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
85	CONSANG	CONSANGUINITY Restrictive definition of consanguinity: where the parents of the malformed case have one or more ancestors in common no more remote than a great-grandparent (=second cousins).	0 = Not related or relationship more distant than second cousin 1 = Relationship of second cousin or closer 9 = Not known
86	SP_CONSANG	SPECIFY TEXT INFORMATION ON CONSANGUINITY	Free text
87	SIBANOM	SIBS WITH ANOMALIES If the sibling (including twin) was notified to EUROCAT fill in variables 90-93 below. Make sure that the local identification numbers given correspond to those in the central database; otherwise give more information in text here. If previous siblings were not notified to EUROCAT specify in text SP_SIBANOM the year of birth and malformations of each sibling. If one sibling has both the same anomaly and a different anomaly, code under "same". If one sibling has the same anomaly and another sibling has a different anomaly, code under "same and other". Always give details in text variable 82 SP_SIBANOM.	1 = Same 2 = Other 3 = Same and other 4 = No 9 = Not known
88	SP_SIBANOM	SPECIFY TYPE OF ANOMALY OF SIBLINGS	Free text
89	PREVSIB	PREVIOUS MALFORMED SIBLINGS NOTIFIED TO EUROCAT If yes, give the local ID number in variables SIB1, SIB2 or SIB3 (variables 91-93). Include malformed co-twins or siblings from the same pregnancy, irrespective of birth order within multiple set. Exclude, conjoined twin.	1 = Yes 2 = No 9 = Not known
90	SIB1	SIB LOCAL ID NUMBER NOTIFIED TO THE CENTRAL REGISTRY Enter here also the code numbers of co-twins or siblings from the same pregnancy, irrespective of birth order within multiple sets. Leave blank if no previous siblings notified to EUROCAT.	Local ID
91	SIB2	AS SIB1	Local ID
92	SIB3	AS SIB1	Local ID
93	MOANOM	MOTHER'S FAMILY WITH ANOMALIES Include mother herself as well as mother's family. Specify type of anomaly in written text and relation to the infant. If the aetiology is known, "same" means the same aetiology, even if the spectrum of malformations present is slightly different.	1 = Same 2 = Other 3 = Same and other 4 = No 9 = Not known

		If the aetiology is unknown or multifactorial, "same" is a matter of judgment by a qualified coder, but full specification of the anomaly should be given, whether other or the same. "Same and other" refers to two different relatives. If a relative has both the same and another anomaly, code "same". Restrict the family to first, second and third degree relatives (mother, father, siblings, grandparents, aunts, uncles, half-siblings, first cousins). Always give details in text variable 95 SP_MOANOM.	
94	SP_MOANOM	SPECIFY TYPE OF ANOMALY AND DESCRIBE THE MALFORMATION	Free text
95	FAANOM	FATHER'S FAMILY WITH ANOMALIES As MOANOM Please give details in text variable 97 SP_FAANOM	As MOANOM
96	SP_FAANOM	SPECIFY TYPE OF ANOMALY AND DESCRIBE THE MALFORMATION	Free text

Sociodemographic (core variables shaded blue)			
Variable Number	**Variable Name**	**Explanation and Instructions**	**Code**
97	MATEDU	MATERNAL EDUCATION Refer to International Standard Classification of Education 2011 (http://uis.unesco.org/sites/default/files/documents/international-standard-classification-of-education-isced-2011-en.pdf). Assign according to the highest level of education completed (or for full-time students, level in progress). Elementary and lower secondary refers to the period of compulsory education, usually to age 15/16. Upper secondary refers to the last two school or college years (usually to age 18) preparing students for tertiary education or the workforce. Tertiary refers to Bachelor's degree (English), Diploma (German), License (French) or equivalent, and to higher degrees (e.g. doctorates), or to other forms of higher education.	1 = Elementary and lower secondary 2 = Upper secondary 3 = Tertiary 9 = Not known
98	SOCM	SOCIOECONOMIC STATUS OF MOTHER Current or last occupation. Upper non-manual – professionals, administrators and managers e.g. doctor, architect, lawyer, banker, manager, teacher, nurse, performer. Lower non-manual – routine non-manual e.g. book-keeper, salesman, receptionist, secretary, computer operator, clerk, waiter. Skilled manual – cook, butcher, carpenter. Unskilled manual – semi and unskilled manual e.g. factory worker, driver, agricultural worker, porter. Self-employed/artisan – owner of shop, restaurant or hotel, independent artisan. Farmer – e.g. self-employed farmer or fisherman. If code 8 ("other/student"), please specify in text in space for general comments (variable 102). For further information see: http://uis.unesco.org/sites/default/files/documents/international-standard-classification-of-education-isced-2011-en.pdf	1 = Upper non-manual 2 = Lower non-manual 3 = Skilled manual 4 = Unskilled manual 5 = Self-employed/artisan 6 = Farmer 8 = Other/student 9 = Not known
99	SOCF	SOCIOECONOMIC STATUS OF FATHER As SOCM.	0 = Single mother, no father recorded 1 = Upper non-manual 2 = Lower non-manual 3 = Skilled manual 4 = Unskilled manual

			5 – Self-employed/artisan 6 = Farmer 8 = Other/student 9 = Not known
100	MIGRANT	MIGRANT STATUS This variable is included to allow assessment of the extent to which services such as prenatal screening are reaching migrants. It does not ask for ethnicity. If code 4, give text details in the general comments section (variable 102).	1 = Mother migrated from outside EU during pregnancy 2 = Mother migrated from outside EU during adult life (from age 18) 3 = Mother not a migrant as defined in 1 or 2 4 = Other (specify in text) 9 = Not known

General Comments (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code
101	GENREM	GENERAL ADDITIONAL COMMENTS	Free text

Last update: 20.02.2025