

2.2.1b Coding Instructions

Baby and Mother (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code
1	CENTRE	<u>CENTRE NUMBER</u>	Code allocated by Central Registry
2	NUMLOC	<u>LOCAL ID</u> 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	<u>DATE OF BIRTH</u> Please enter dates as a numeric string, not in date format (eg. do not use 28/02/89 or 28-02-89, instead use 280289). Cases reported with unknown date of birth will not be included in cluster analysis.	Day, month, year 99 = Not known for day and month DO NOT TRANSMIT RECORDS IF YEAR OF BIRTH IS NOT KNOWN
4	SEX	<u>SEX</u> 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 or other problems, indicate as "not known".	1 = Male 2 = Female 3 = Indeterminate 9 = Not known
5	NBRBABY	<u>NUMBER OF BABIES/FETUSES DELIVERED</u> Fill out a separate form for each malformed baby/fetus in a multiple set. Only one form 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 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

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Variable Number	Variable Name	Explanation and Instructions	Code
6	SP_TWIN	<u>SPECIFY TWIN TYPE OF BIRTH</u> (malformed and non-malformed), like or unlike sex, zygosity	Free text
7	NBRMALF	<u>NUMBER OF MALFORMED IN MULTIPLE SET</u> 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	<u>TYPE OF BIRTH</u> Birth with type of birth not known should be transmitted to EUROCAT, but will be excluded from routine EUROCAT analysis. EUROCAT includes all livebirths, fetal deaths with gestational age (GA) ≥ 20 weeks and terminations of pregnancy (at any gestational age) after prenatal diagnosis of malformation. Fetal deaths with GA < 20 weeks (code = 3) may be reported to EUROCAT but will not be included in prevalence data. 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 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 a 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 = date of reduction; and code carefully all multiple birth variables).	1 = Live birth 2 = Stillbirth 3 = Spontaneous abortion 4 = TOPFA 9 = Not known

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Variable Number	Variable Name	Explanation and Instructions	Code
9	CIVREG	<p><u>CIVIL REGISTRATION STATUS</u> Livebirths and stillbirths are civilly registered leading to either a birth or stillbirth certificate and appear in official birth statistics for your region.</p> <p>Code here whether this case fulfilled the conditions for live or stillbirth registration in your country.</p>	1 = Livebirth 2 = Stillbirth 3 = No civil registration 9 = Not known
10	WEIGHT	<p><u>BIRTH WEIGHT</u> Give weight in grams.</p>	9999 = Not known (Do not use 99 or 999 for “Not Known” as this will be considered the birth weight).
11	GESTLENGTH	<p><u>LENGTH OF GESTATION IN COMPLETED WEEKS</u> 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 fetocide.</p>	99 = Not known
12	SURVIVAL	<p><u>SURVIVAL BEYOND ONE WEEK OF AGE</u> Yes = Child known to be alive after one week.</p> <p>No = Child known to have died before or during first week (including stillbirths and abortions).</p> <p>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.</p> <p>If survival at one week is unknown, but survival at discharge from maternity unit less than one week is known, use the latter.</p> <p>The definition of first week of life varies between countries. Follow your country’s perinatal mortality definition and specify this in your Registry Description.</p> <p>Not known = Not known if child has died during first week.</p>	1 = Yes 2 = No 3 = Alive at discharge <1 week 9 = Not known

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Variable Number	Variable Name	Explanation and Instructions	Code
13	DEATH_DATE	<p><u>DATE OF DEATH</u> For livebirths only.</p> <p>Please enter dates as a numeric string, not in date format (eg. do not use 28/02/89 or 28-02-89, instead use 280289).</p>	<p>Day, month, year 99= Died, not known day or month 44 =Died, not known year (Do not use 99 for “not known” year of death, as this will be read as died in 1999, day and month not known.)</p> <p>222222= Known to be alive at 1 year 333333= Not known if alive or dead at 1 year</p>
14	DATEMO	<p><u>DATE OF BIRTH OF MOTHER</u> Give as much information as is known eg. Feb 1963 = 990263, 1963 = 999963. Please enter dates as a numeric string, not in date format (eg. do not use 28/02/89 or 28-02-89, instead use 280289).</p> <p>This variable can be used to calculate maternal age at Expected Date of Delivery for preterm deliveries and terminations.</p>	<p>Day, month, year 99 = Not known day or month 44 = Not known year</p>
15	AGEMO	<p><u>AGE OF THE MOTHER AT DELIVERY</u> 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.</p>	<p>99 = Not known</p>
16	BMI	<p><u>MATERNAL BODY MASS INDEX</u> Enter BMI (2 digits). The EDMP 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 mother known to be obese, enter code for obesity E660 in maternal illness before pregnancy (variable 60)</p> <p>Whilst BMI is a new variable 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</p>	<p>2 digits Expected range 15 – 50</p> <p>97 = exact BMI NK but <30 98 = exact BMI NK but >=30 99 = Not known</p>
17	RESIDMO	<p><u>MOTHER’S RESIDENCE CODE</u> Use local code for locality of residence at time of delivery.</p>	<p>Local code (up to 10 digits)</p>
18	TOTPREG	<p><u>TOTAL NUMBER OF PREVIOUS PREGNANCIES</u> NOTE – The current reported pregnancy is NOT included.</p> <p>Include all previous abortions whether spontaneous or induced. Multiple pregnancies count as 1 in the total</p>	<p>00 = None 01 = One 02 = Two 03 = Three etc 20 = Twenty or more 99 = Not known</p>

Diagnosis (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code
19	WHENDISC	<p><u>WHEN DISCOVERED</u> When the baby was first suspected of having a congenital anomaly.</p> <p>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 prenatal diagnosis is made when fetus is dead code 1 (for stillbirths) or 7 (for spontaneous abortions).</p> <p>For livebirths: when first suspicion of an anomaly was at death OR at postmortem, when discovered is age at death (eg. At birth, < 1 week, 1-4 weeks etc).</p> <p>For stillbirths: when first suspicion of an anomaly was at birth OR at postmortem, when discovered is at birth (eg. Code = 1).</p> <p>All cases MUST have been confirmed as having a congenital anomaly</p> <p>Please also complete variables 12 "SURVIVAL", 13 "DEATH-DATE", 20 "CONDISC" and 28 "PM".</p>	1 = At birth 2 = Less than 1 week 3 = 1-4 weeks 4 = 1-12 months 5 = Over 12 months 6 = Prenatal diagnosis in <u>live</u> fetus 7 = At abortion (spontaneous) 9 = Not known 10 = Postnatal diagnosis, age not known
20	CONDISC	<p><u>CONDITION AT DISCOVERY</u> Condition of fetus or baby when malformation was first suspected.</p>	1 = Alive 2 = Dead 9 = Not known
21	AGEDISC	<p><u>IF PRENATALLY DIAGNOSED, GESTATIONAL AGE AT DISCOVERY IN COMPLETED WEEKS</u> GA as defined in variable gestlength.</p> <p>Gestational age at which the fetus was first suspected to be malformed (EXCLUDING soft markers). Indicate time of examination rather than time when result known.</p> <p>If no prenatal diagnosis please leave blank.</p>	99 = Not known

Diagnosis (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code
22	FIRSTPRE	<p><u>FIRST POSITIVE PRENATAL TEST</u> This refers to the first prenatal test whether screening procedure or diagnostic test which indicated a possible congenital anomaly or need for further tests.</p> <p>For code 7 = other specified test, give information in text field (variable 23).</p> <p>If test performed and result negative, then the “When discovered” variable cannot be coded 6 (prenatal diagnosis).</p> <p>This field is to record what DID happen, not any possible plans or intentions. Ultrasound < 14 weeks means only ultrasound performed which may include a nuchal measurement. The serum/combined screening must involve a biochemical test</p>	<p>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 = CVS or amniocentesis 7 = Other test positive 8 = Test(s) performed, result negative 9 = Not known 10 = No test performed 11 = Fetal karyotype on maternal blood</p>
23	SP_FIRSTPRE	<p><u>SPECIFY “OTHER” FIRST PRENATAL TEST</u> If FIRSTPRE = 7, specify which positive prenatal test</p>	Free text
24	KARYO	<p><u>KARYOTYPE OF INFANT/FETUS</u> Specify result in variable 25. Array results count as a karyotype test</p> <p>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)</p> <p>If performed and results known, please specify (according to the latest ISCN edition).</p> <p>“Probe test performed” refers to FISH, PCR, or other analyses restricted to specific chromosomal regions .</p> <p>“Failed” refers to a technical failure where a repeat examination could not be done and the karyotype is therefore unknown.</p>	<p>1 = Performed, result known 2 = Performed, results not known 3 = Not performed 4 = Probe test performed 8 = Failed 9 = Not known</p>

Diagnosis (core variables shaded blue)

Variable Number	Variable Name	EXPLANATION AND INSTRUCTIONS	Code
25	SP_KARYO	<p><u>SPECIFY KARYOTYPE OR CHROMOSOMAL MICROARRAY</u></p> <p>EXAMPLES:</p> <p>47,XY,+21</p> <p>46,XX,del(2)(p13p23)mat Description: An interstitial deletion resulting from mal-segregation of a maternal insertion</p> <p>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</p> <p>arr(1-22)×3,(X)×2,(Y)×1 Description: Microarray analysis shows triploidy 69,XXY</p> <p>arr(8)×3,(21)×3 Description: Microarray analysis shows a single copy gain of chromosomes 8 and 21.</p> <p>46,XY.rsa(13,18,21)×2,(X,Y)×1 Description: normal chromosomes, only chromosome 13,18,21, X and Y investigated</p> <p>rsa 22q11.2('kit name')×1 Description: microdeletion 22q.11.2 diagnosed by multiple ligation probe amplification method (MLPA)</p>	Free text
26	GENTEST	<p><u>GENETIC TEST</u></p> <p>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</p> <p>Whilst GENETIC TEST is a new variable 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</p> <p>If the test is performed but the result not yet known, please wait for the result before reporting</p>	<p>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</p>
27	SP_GENTEST	<p><u>SPECIFY TYPE OF GENETIC TEST</u></p> <p>Give method used and the result of the test (type of mutation and which gene)</p> <p>Examples: Single gene analysis, exome sequencing, whole genome sequencing</p>	Free text

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Variable Number	Variable Name	Explanation and Instructions	Code
28	PM	<p><u>POST MORTEM EXAMINATION</u></p> <p>If performed record the malformation(s) discovered in the “malformation” section in the form. If other findings record in the “comments” space (variable 95).</p> <p>“Results known” means that the autopsy record has been reviewed by the registry.</p> <p>“Results not known” means that the autopsy record was not available to the registry.</p> <p>“Macerated fetus” means that although a post mortem was performed, maceration of the fetus prevented a full protocol from being followed.</p>	<p>1 = Performed, results known 2 = Performed, results not known 3 = Not performed 4 = Macerated fetus 9 = Not known</p>
29	SURGERY	<p><u>FIRST SURGICAL PROCEDURE FOR MALFORMATION (PERFORMED OR EXPECTED)</u></p> <p>Complete for all livebirths (and fetal deaths, only if there was prenatal surgery)</p> <p>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.</p> <p>“No surgery required” means that this case does not have a severe enough malformation, or that the malformation is not correctable by surgery.</p> <p>“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.</p>	<p>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 9 = Not known</p>
30	SYNDROME	<p><u>SYNDROME OR ASSOCIATION</u></p> <p>Use this variable for genetic syndromes, skeletal dysplasias, teratogenic syndromes, associations, microdeletions and chromosomal anomalies.</p> <p>Refer to EUROCAT Guide on syndromes. Give 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.</p> <p>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 MALF01.</p> <p>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.</p> <p>Local registries are advised to keep photographs and x-ray images of all syndrome cases if possible, as the diagnosis is predominantly established on the basis of specific facial dysmorphism.</p>	<p>ICD 10</p> <p>First 4 digits are ICD10 5th digit = BPA supplement or leave blank</p>

Diagnosis (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code
31	SP-SYNDROME	<u>SPECIFY SYNDROME</u> Written text description of the ICD10 code in variable 30	
32	MALFO1	<u>MALFORMATION</u> A baby/fetus with ONLY minor anomalies (see exclusion list, chapter 7) should not be transmitted to Central Registry. When a major anomaly is present, code both major and minor anomalies. In case of conjoined twins, give 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 8 th anomaly (text variable 47 SP_MALFO8). Include in the 8 specified codes the most important ones, or those tabulated in EUROCAT Reports. Give written description of the malformations available in malformation text variables 33, 35, 37, 39, 41, 43, 45 and 47.	ICD 10 First 4 digits are ICD 5 th digit = BPA classification OR leave blank
33	SP_MALFO1	<u>SPECIFY MALFORMATION</u>	Free text
34	MALFO2	As MALFO1	As MALFO1
35	SP_MALFO2	<u>SPECIFY MALFORMATION</u>	Free text
36	MALFO3	As MALFO1	As MALFO1
37	SP_MALFO3	<u>SPECIFY MALFORMATION</u>	Free text
38	MALFO4	As MALFO1	As MALFO1
39	SP_MALFO4	<u>SPECIFY MALFORMATION</u>	Free text
40	MALFO5	As MALFO1	As MALFO1
41	SP_MALFO5	<u>SPECIFY MALFORMATION</u>	Free text
42	MALFO6	As MALFO1	As MALFO1
43	SP_MALFO6	<u>SPECIFY MALFORMATION</u>	Free text
44	MALFO7	As MALFO1	As MALFO1
45	SP_MALFO7	<u>SPECIFY MALFORMATION</u>	Free text
46	MALFO8	As MALFO1	As MALFO1
47	SP_MALFO8	<u>SPECIFY MALFORMATION</u>	Free text

Diagnosis (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions			Code
48	PRESYN	<p><u>PRENATAL DIAGNOSIS FOR SYNDROME</u> 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 <i>exact</i> anomaly was not correctly diagnosed. 'Yes, prenatally diagnosed', should be used when the prenatal finding is nearly 100% predictive of the congenital anomaly. 'Partially' means that the prenatal finding is consistent with the postnatal anomaly but has a lesser predictive value, being suggestive of more than one type of anomaly, an example here would be increased nuchal translucency. The examples below are to illustrate this principle and ensure consistency of coding. Queries about individual cases can be send to Central registry</p>			<p>1 = Yes, this anomaly was diagnosed prenatally 2 = No, this anomaly was diagnosed postnatally 3 = This anomaly partially prenatally diagnosed 9 =Not known</p>
		<p><u>Prenatal Finding</u></p> <p>Double bubble</p> <p>High risk screening (no amnio)</p> <p>Ventriculomegaly</p> <p>Ventriculomegaly</p> <p>Ventriculomegaly</p> <p>Significant heart anomaly</p> <p>Heart abnormality</p> <p>Cleft lip</p> <p>IUGR</p> <p>Anhydramnios</p> <p>Micrognathia</p> <p>Severe skeletal dysplasia</p> <p>Echogenic bowel</p> <p>Absent stomach bubble</p>	<p><u>Postnatal finding</u></p> <p>Duodenal atresia/stenosis</p> <p>T21</p> <p>Agenesis corpus callosum</p> <p>Neuronal migration anomalies</p> <p>Hydrocephalus</p> <p>Any significant heart anomaly</p> <p>22q11 del</p> <p>Cleft lip and palate</p> <p>Skeletal displasia</p> <p>Renal agenesis</p> <p>Pierre Robin/cleft palate</p> <p>Specific skeletal dysplasia eg thanatophoric/achondrogenesis</p> <p>CF</p> <p>Oesophageal atresia</p>	<p><u>Prenatal/Postnatal/Partial</u></p> <p>Prenatal</p> <p>Partial</p> <p>Partial</p> <p>Partial</p> <p>Prenatal</p> <p>Prenatal</p> <p>Partial</p> <p>Partial</p> <p>Postnatal</p> <p>Partial</p> <p>Prenatal</p> <p>Prenatal</p> <p>Partial</p> <p>Partial</p>	

Diagnosis (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code
49	PREMAL1	<u>PRENATAL DIAGNOSIS FOR MALFORMATION</u> AS PRESYN	<u>AS PRESYN</u>
50	PREMAL2	<u>PRENATAL DIAGNOSIS FOR MALFORMATION</u> AS PRESYN	<u>AS PRESYN</u>
51	PREMAL3	<u>PRENATAL DIAGNOSIS FOR MALFORMATION</u> AS PRESYN	<u>AS PRESYN</u>
52	PREMAL4	<u>PRENATAL DIAGNOSIS FOR MALFORMATION</u> AS PRESYN	<u>AS PRESYN</u>
53	PREMAL5	<u>PRENATAL DIAGNOSIS FOR MALFORMATION</u> AS PRESYN	<u>AS PRESYN</u>
54	PREMAL6	<u>PRENATAL DIAGNOSIS FOR MALFORMATION</u> AS PRESYN	<u>AS PRESYN</u>
55	PREMAL7	<u>PRENATAL DIAGNOSIS FOR MALFORMATION</u> AS PRESYN	<u>AS PRESYN</u>
56	PREMAL8	<u>PRENATAL DIAGNOSIS FOR MALFORMATION</u> AS PRESYN	<u>AS PRESYN</u>
57	OMIM	<p><u>OMIM / TYPE OF MENDELIAN INHERITANCE</u></p> <p>To be coded by medical geneticist or after advice from medical geneticist.</p> <p>This code is to be used for cases with single gene origin only – Refer to EUROCAT Syndrome Guide.</p> <p>The first digit may be filled in without the rest of the code if the full OMIM code is not known.</p> <p>Full codes can be found on the OMIM website http://www.ncbi.nlm.nih.gov/omim/</p>	
58	ORPHA	<p>This code is to be used for rare diseases including congenital anomalies, chromosomal, teratogenic and genetic syndromes.</p> <p>Use the link and enter the name of the condition. if more than one code/disease appears, select the most specific orpha code. If you do not have specific information about genetic background or phenotype, select the most general orpha code.</p> <p>https://www.orpha.net/consor/cgi-bin/Disease.php?lng=EN</p>	

Exposure (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code
59	ASSCONCEPT	<p><u>ASSISTED CONCEPTION</u></p> <p>IVF = In vitro fertilization</p> <p>GIFT = Gamete intra fallopian transfer</p> <p>ICSI = Intracytoplasmic sperm injection</p>	<p>0 = No</p> <p>1 = Induced ovulation only</p> <p>2 = Artificial insemination</p> <p>3 = IVF</p> <p>4 = GIFT</p> <p>5 = ICSI</p> <p>6 = Egg donation</p> <p>8 = Other</p> <p>9 = Not known</p> <p>10 = Assisted conception, type unknown</p>
60	OCCUPMO	<p><u>MOTHER'S OCCUPATION AT TIME OF CONCEPTION</u></p> <p>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.</p> <p>Code according to 2008 (ISCO-08) Classification for births with birth dates from 2013.</p> <p>Code according to the 1988 International Standard Classification of Occupations (ISCO-88) for births with birth dates up to 2012.</p> <p>Links for ISCO classifications: http://www.ilo.org/public/english/bureau/stat/isco/isco08/index.htm Available in many languages.</p> <p>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</p> <p>EUROCAT Supplement: 9991 = Employed (including self-employed), but occupation unknown 9995 = Housewife 9996 = Student 9997 = Unemployed 9999 = Not known whether employed or not</p>	<p>4 digit code</p> <p>9999 = Not known</p> <p>(do NOT use 9, 99 or 999 for not known)</p>

Exposure (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code																										
61	ILLBEF1	<p><u>ILLNESS BEFORE PREGNANCY 1</u></p> <p>Record any illness whether chronic or acute with onset before pregnancy and that may affect fetal development (eg. childhood cancer, metabolic and endocrine disease, severe congenital anomaly). Code according to ICD10. The codes mentioned below are only examples.</p> <p>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)</p> <p>Abridged list:</p> <table border="0"> <tr><td>Hyperthyroidism</td><td>E050 - E059</td></tr> <tr><td>Hypothyroidism</td><td>E000 - E039</td></tr> <tr><td>Diabetes Type 1</td><td>E100 - E109</td></tr> <tr><td>Diabetes Type 2</td><td>E110 - E119</td></tr> <tr><td>Obesity</td><td>E660 - E669</td></tr> </table> <p>If maternal BMI \geq 30 give code for obesity</p> <table border="0"> <tr><td>Metabolic disorders</td><td>E700 – E889</td></tr> <tr><td>Anorexia /eating disorders</td><td>F500-F509</td></tr> <tr><td>Depression</td><td>F320 – F339</td></tr> <tr><td>Epilepsy</td><td>G400 - G409</td></tr> <tr><td>Hypertension</td><td>I100 - I159</td></tr> <tr><td>Asthma</td><td>J450 - J459</td></tr> <tr><td>Chronic alcoholism</td><td>F102</td></tr> <tr><td>Drug addict</td><td>F112 - F122 - F132 - F142</td></tr> </table> <p>COVID-19 (only report if within 3 months before pregnancy): B342, U071, U072</p> <p><i>U07.1: COVID-19, virus identified (Use this code when COVID-19 has been confirmed by laboratory testing irrespective of severity of clinical signs or symptoms.)</i></p> <p><i>U07.2: COVID-19, virus not identified (Use this code when COVID-19 is diagnosed clinically or epidemiologically but laboratory testing is inconclusive or not available)</i></p> <p><i>B34.2: Coronavirus infection, unspecified site.</i></p>	Hyperthyroidism	E050 - E059	Hypothyroidism	E000 - E039	Diabetes Type 1	E100 - E109	Diabetes Type 2	E110 - E119	Obesity	E660 - E669	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	<p>ICD 10</p> <p>0 = No illness</p> <p>1 = Yes, but no information available</p> <p>9 = Not known</p>
Hyperthyroidism	E050 - E059																												
Hypothyroidism	E000 - E039																												
Diabetes Type 1	E100 - E109																												
Diabetes Type 2	E110 - E119																												
Obesity	E660 - E669																												
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																												
62	ILLBEF2	<p><u>ILLNESS BEFORE PREGNANCY 2 - AS FOR ILLBEF1</u></p>																											

Exposure (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code
63	MATDIAB	<p>MATERNAL PREGESTATIONAL DIABETES</p> <p>This variable is specifically for pregestational diabetes. Gestational diabetes is dealt with under the 'illness during pregnancy' variable (variable 64)</p> <p>Type 1 diabetes: characterized by hyperglycemia due to an absolute deficiency of the insulin hormone produced by the pancreas</p> <p>An HbA1c of 48mmol/mol is recommended as the cut-off point for diagnosing diabetes.</p> <p>Type 2 diabetes: characterized by hyperglycemia due to a defect in insulin secretion</p> <p>An HbA1c of 48mmol/mol is recommended as the cut-off point for diagnosing diabetes.</p> <p>*Maturity Onset Diabetes in the Young (MODY) displays an autosomal dominant pattern of inheritance</p> <p>An HbA1c of 48mmol/mol is recommended as the cut-off point for diagnosing diabetes.</p> <p>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) http://www.who.int/diabetes/publications/en/</p>	<p>1= Yes, type 1 diabetes (IDDM)</p> <p>2= Yes, type 2 diabetes (NIDDM)</p> <p>3 = Yes, type MODY* (all types)</p> <p>4 = Yes, type not known</p> <p>5 = No, but impaired glucose intolerance</p> <p>6 = No pregestational diabetes</p> <p>9 = Not known</p>

Exposure (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code																																																																																																																																																																																																																												
64	HbA1c	<p><u>GLYCATED HAEMOGLOBIN (HbA1c) VALUE</u></p> <p>Give the first HbA1c value measured in the first trimester (in mmol/mol units)</p> <p>Normal values for non-diabetic individuals <48mmol/mol</p> <table border="1"> <tbody> <tr><td>%</td><td>4.0</td><td>4.1</td><td>4.2</td><td>4.3</td><td>4.4</td><td>4.5</td><td>4.6</td><td>4.7</td><td>4.8</td><td>4.9</td></tr> <tr><td>mmol/mol</td><td>20</td><td>21</td><td>22</td><td>23</td><td>25</td><td>26</td><td>27</td><td>28</td><td>29</td><td>30</td></tr> <tr><td>%</td><td>5.0</td><td>5.1</td><td>5.2</td><td>5.3</td><td>5.4</td><td>5.5</td><td>5.6</td><td>5.7</td><td>5.8</td><td>5.9</td></tr> <tr><td>mmol/mol</td><td>31</td><td>32</td><td>33</td><td>34</td><td>36</td><td>37</td><td>38</td><td>39</td><td>40</td><td>41</td></tr> <tr><td>%</td><td>6.0</td><td>6.1</td><td>6.2</td><td>6.3</td><td>6.4</td><td>6.5</td><td>6.6</td><td>6.7</td><td>6.8</td><td>6.9</td></tr> <tr><td>mmol/mol</td><td>42</td><td>43</td><td>44</td><td>45</td><td>46</td><td>48</td><td>49</td><td>50</td><td>51</td><td>52</td></tr> <tr><td>%</td><td>7.0</td><td>7.1</td><td>7.2</td><td>7.3</td><td>7.4</td><td>7.5</td><td>7.6</td><td>7.7</td><td>7.8</td><td>7.9</td></tr> <tr><td>mmol/mol</td><td>53</td><td>54</td><td>55</td><td>56</td><td>57</td><td>58</td><td>60</td><td>61</td><td>62</td><td>63</td></tr> <tr><td>%</td><td>8.0</td><td>8.1</td><td>8.2</td><td>8.3</td><td>8.4</td><td>8.5</td><td>8.6</td><td>8.7</td><td>8.8</td><td>8.9</td></tr> <tr><td>mmol/mol</td><td>64</td><td>65</td><td>66</td><td>67</td><td>68</td><td>69</td><td>70</td><td>72</td><td>73</td><td>74</td></tr> <tr><td>%</td><td>9.0</td><td>9.1</td><td>9.2</td><td>9.3</td><td>9.4</td><td>9.5</td><td>9.6</td><td>9.7</td><td>9.8</td><td>9.9</td></tr> <tr><td>mmol/mol</td><td>75</td><td>76</td><td>77</td><td>78</td><td>79</td><td>80</td><td>81</td><td>83</td><td>84</td><td>85</td></tr> <tr><td>%</td><td>10.0</td><td>10.1</td><td>10.2</td><td>10.3</td><td>10.4</td><td>10.5</td><td>10.6</td><td>10.7</td><td>10.8</td><td>10.9</td></tr> <tr><td>mmol/mol</td><td>86</td><td>87</td><td>88</td><td>89</td><td>90</td><td>91</td><td>92</td><td>93</td><td>95</td><td>96</td></tr> <tr><td>%</td><td>11.0</td><td>11.1</td><td>11.2</td><td>11.3</td><td>11.4</td><td>11.5</td><td>11.6</td><td>11.7</td><td>11.8</td><td>11.9</td></tr> <tr><td>mmol/mol</td><td>97</td><td>98</td><td>99</td><td>100</td><td>101</td><td>102</td><td>103</td><td>104</td><td>105</td><td>107</td></tr> <tr><td>%</td><td>12.0</td><td>12.1</td><td>12.2</td><td>12.3</td><td>12.4</td><td>12.5</td><td>12.6</td><td>12.7</td><td>12.8</td><td>12.9</td></tr> <tr><td>mmol/mol</td><td>108</td><td>109</td><td>110</td><td>111</td><td>112</td><td>113</td><td>114</td><td>115</td><td>116</td><td>117</td></tr> <tr><td>%</td><td>13.0</td><td>13.1</td><td>13.2</td><td>13.3</td><td>13.4</td><td>13.5</td><td>13.6</td><td>13.7</td><td>13.8</td><td>13.9</td></tr> <tr><td>mmol/mol</td><td>119</td><td>120</td><td>121</td><td>122</td><td>123</td><td>124</td><td>125</td><td>126</td><td>127</td><td>128</td></tr> </tbody> </table>	%	4.0	4.1	4.2	4.3	4.4	4.5	4.6	4.7	4.8	4.9	mmol/mol	20	21	22	23	25	26	27	28	29	30	%	5.0	5.1	5.2	5.3	5.4	5.5	5.6	5.7	5.8	5.9	mmol/mol	31	32	33	34	36	37	38	39	40	41	%	6.0	6.1	6.2	6.3	6.4	6.5	6.6	6.7	6.8	6.9	mmol/mol	42	43	44	45	46	48	49	50	51	52	%	7.0	7.1	7.2	7.3	7.4	7.5	7.6	7.7	7.8	7.9	mmol/mol	53	54	55	56	57	58	60	61	62	63	%	8.0	8.1	8.2	8.3	8.4	8.5	8.6	8.7	8.8	8.9	mmol/mol	64	65	66	67	68	69	70	72	73	74	%	9.0	9.1	9.2	9.3	9.4	9.5	9.6	9.7	9.8	9.9	mmol/mol	75	76	77	78	79	80	81	83	84	85	%	10.0	10.1	10.2	10.3	10.4	10.5	10.6	10.7	10.8	10.9	mmol/mol	86	87	88	89	90	91	92	93	95	96	%	11.0	11.1	11.2	11.3	11.4	11.5	11.6	11.7	11.8	11.9	mmol/mol	97	98	99	100	101	102	103	104	105	107	%	12.0	12.1	12.2	12.3	12.4	12.5	12.6	12.7	12.8	12.9	mmol/mol	108	109	110	111	112	113	114	115	116	117	%	13.0	13.1	13.2	13.3	13.4	13.5	13.6	13.7	13.8	13.9	mmol/mol	119	120	121	122	123	124	125	126	127	128	<p>999 = Not known</p> <p>3 digits</p>
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Exposure (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code
65	ILLDUR1	<p><u>ILLNESS DURING PREGNANCY</u></p> <p>Record 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</p> <p>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). Do not insert the decimal point in the code (eg. Code B34.1 as B341)</p> <p>Gestational Diabetes O244 – O249</p> <p>Haemorrhage early pregnancy O200 – O209</p> <p>Hyperemesis O210 - O219</p> <p>Coxsackie's B341</p> <p>Cytomegalic Inclusion Diseases B250 - B259</p> <p>Herpes Simplex B000 - B009</p> <p>HIV (AIDS) B200 - B249</p> <p>Influenza J100 - J119</p> <p>Listeria A320 - A329</p> <p>Mumps B260 - B269</p> <p>Rubella B060 - B069</p> <p>Syphillis A530 - A539</p> <p>Toxoplasmosis B580 - B589</p> <p>Varicella (Chicken Pox) B010 - B019</p> <p>Viral Hepatitis B190 - B199</p> <p>Zika virus A928</p> <p>Drug poisoning T360-T509</p> <p>COVID-19 B342 & U071, U072</p> <p><i>U07.1: COVID-19, virus identified (Use this code when COVID-19 has been confirmed by laboratory testing irrespective of severity of clinical signs or symptoms.)</i></p> <p><i>U07.2: COVID-19, virus not identified (Use this code when COVID-19 is diagnosed clinically or epidemiologically but laboratory testing is inconclusive or not available)</i></p> <p><i>B34.2: Coronavirus infection, unspecified site.</i></p>	<p>ICD 10</p> <p>0 = No</p> <p>1 = Yes, but no information available</p> <p>9 = Not known</p>
66	ILLDUR2	<p><u>ILLNESS DURING PREGNANCY</u></p> <p>AS FOR ILLDUR1</p>	
67	FOLIC_G14	<p><u>FOLIC ACID SUPPLEMENTATION</u></p> <p>Recommend to your local maternity hospitals or midwives to collect these data.</p> <p>Folic acid supplementations include folic acid only tablets, a multivitamin preparation which contains folic acid or contraceptive pills which contain folic acid.</p> <p>If the folic acid dose is high, please add the code B03BB01 in the drugs variable</p>	<p>1 = Folic acid taken pre and post-conceptionally</p> <p>2 = Folic acid taken only post-conceptionally</p> <p>3 = Folic acid not taken</p> <p>4 = Folic acid taken, timing unknown</p> <p>9 = Not known if folic acid taken</p>

Exposure (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code
68	FIRSTTRI	<p><u>FIRST TRIMESTER MEDICATION</u></p> <p>“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.</p> <p>“Undetermined” means that the usual data sources were consulted, but</p> <ul style="list-style-type: none"> it was not clearly stated that medication was either taken or not taken the information regarding medication use was illegible Type of medication is unknown. <p>“Medication taken but timing unknown” means that the usual data sources stated that medication was taken but the timing of use was not stated for some or all of the medications.</p> <p>Use this option also for cases in which the data sources clearly state that certain medication was taken in the first trimester, but for other medication the timing was unknown. Use SP_DRUGS fields to explain for each recorded medication whether it was taken in the first trimester, or if timing was unknown.</p> <p>“Not Known” means that the usual data sources were not found.</p> <p>Only fill in DRUGS1-5 and EXTRADRUGS if you have coded FIRSTTRI = 1 (Yes medication taken) or = 4 (Medication taken, but timing unknown).</p> <p>If you have coded FIRSTTRI = 2 (no medication taken), FIRSTTRI = 3 (undetermined) or FIRSTTRI = 9 (unknown), there shouldn't be any ATC codes in any of the DRUGS variables</p> <ul style="list-style-type: none"> 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 (eg. 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 Do not include usual vitamins and mineral supplementation, but include unusual intakes of vitamins or minerals (eg. Vitamin A mega doses). Only medication taken at physiologic doses should be included. <p>Whilst FIRSTTRI is a new variable 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</p>	<p>1 = Yes, medication taken in first trimester</p> <p>2 = No medication taken in first trimester</p> <p>3 = Undetermined</p> <p>4 = Medication taken, but timing unknown</p> <p>9 = Not Known</p>

Exposure (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code
69	DRUGS1	<p><u>DRUGS - 7 DIGITS MAXIMUM</u></p> <p>Record any drug taken by the mother during the first trimester of pregnancy (from the 1st day of last menstrual period up to the 12th week of gestation). Drugs with long elimination half time and taken before conception should also be recorded (eg. Acitretin, etretinate etc).</p> <p>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.</p> <p>Use ATC-coding and use as many digits as possible (from 3 to 7). Website http://www.whocc.no/atcddd/.</p> <p>Do not record usual vitamins and mineral supplementation, but record unusual intakes of vitamins or minerals (eg. 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.</p> <p>ATC example: N03A: antiepileptic drug N03AF01: carbamazepine</p> <p>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.</p> <p>If a drug overdose or self-poisoning, this MUST be explained in the drug description.</p>	
70	SP_DRUGS1	<u>SPECIFY DRUG EXPOSURES</u>	Free text
71	DRUGS2	<p><u>AS FOR DRUGS1</u></p> <p>Please give details in text variable 71 SP_DRUGS2.</p>	As for DRUGS1
72	SP_DRUGS2	<u>SPECIFY DRUG EXPOSURES</u>	Free text
73	DRUGS3	<p><u>AS FOR DRUGS1</u></p> <p>Please give details in text variable 73 SP_DRUGS3.</p>	As for DRUGS1
74	SP_DRUGS3	<u>SPECIFY DRUG EXPOSURES</u>	Free text
75	DRUGS4	<p><u>AS FOR DRUGS1</u></p> <p>Please give details in text variable 75 SP_DRUGS3.</p>	
76	SP_DRUGS4	<u>SPECIFY DRUG EXPOSURES</u>	
77	DRUGS5	<p><u>AS FOR DRUGS1</u></p> <p>Please give details in text variable 77 SP_DRUGS3.</p>	
78	SP_DRUGS5	<u>SPECIFY DRUG EXPOSURES</u>	

Exposure (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code
79	EXTRA_DRUGS	<p><u>EXTRA DRUGS</u></p> <p>This field is only to be used if drug fields 1-5 have already been filled.</p> <p>Record any drug taken by the mother during the first trimester of pregnancy (from the 1st day of last menstrual period up to the 12th week of gestation). Drugs with long elimination half time and taken before conception should also be recorded (eg. Acitretin, etretinate etc).</p> <p>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.</p> <p>Use ATC-coding and use as many digits as possible (from 3 to 7). Website http://www.whocc.no/atcddd/.</p> <p>Do not record usual vitamins and mineral supplementation, but record unusual intakes of vitamins or minerals (eg. 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.</p> <p>ATC example: N03A: antiepileptic drug N03AF01: carbamazepine</p> <p>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.</p> <p>Only drugs taken at physiologic doses to be recorded.</p> <p>If a drug overdose or self-poisoning, this MUST be explained in the drug description.</p> <p><u>If importing data from a local program</u>, enter the ATC code and text description in the following format:</p> <p style="text-align: center;"><ATC code text description></p> <p>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:</p> <p><ATC code text description><ATC code text description></p> <p>For example a case with valproate and lamotrigine exposure is entered in the extra_drugs field as: <N03AG01 Valproate><N03AX09 Lamotrigine></p> <p>(See chapter 2.4 of EDMP User Guide for further guidance)</p>	

Exposure (core variables shaded blue)

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

Family History (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code
86	CONSANG	<u>CONSANGUINITY</u> 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
87	SP_CONSANG	<u>SPECIFY TEXT INFORMATION ON CONSANGUINITY</u>	Free text
88	SIBANOM	<u>SIBS WITH ANOMALIES</u> If the sibling (including twin) was notified to EUROCAT fill in variables 83-86 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
89	SP_SIBANOM	<u>SPECIFY TYPE OF ANOMALY OF SIBLINGS</u>	Free text
90	PREVSIB	<u>PREVIOUS MALFORMED SIBLINGS NOTIFIED TO EUROCAT</u> If yes, give the local ID number in variables SIB1, SIB2 or SIB3 (variables 84-86). 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
91	SIB1	<u>SIB LOCAL ID NUMBER NOTIFIED TO THE CENTRAL REGISTRY</u> 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
92	SIB2	<u>As SIB1</u>	Local ID
93	SIB3	<u>As SIB1</u>	Local ID

Family History (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code
94	MOANOM	<p><u>MOTHER'S FAMILY WITH ANOMALIES</u></p> <p>Include mother herself as well as mother's family. Specify type of anomaly in written text and relation to the infant.</p> <p>If the aetiology is known, "same" means the same aetiology, even if the spectrum of malformations present is slightly different.</p> <p>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.</p> <p>"Same and other" refers to two different relatives. If a relative has both the same and another anomaly, code "same".</p> <p>Restrict the family to first, second and third degree relatives (mother, father, siblings, grandparents, aunts, uncles, half-siblings, first cousins).</p> <p>Always give details in text variable 88 SP_MOANOM.</p>	1 = Same 2 = Other 3 = Same and other 4 = No 9 = Not known
95	SP_MOANOM	<u>SPECIFY TYPE OF ANOMALY AND DESCRIBE THE MALFORMATION</u>	Free text
96	FAANOM	<p><u>FATHER'S FAMILY WITH ANOMALIES</u></p> <p>As MOANOM</p> <p>Please give details in text variable 90 SP_FAANOM</p>	As MOANOM
97	SP_FAANOM	<u>SPECIFY TYPE OF ANOMALY AND DESCRIBE THE MALFORMATION</u>	Free text

Sociodemographic (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code
98	MATEDU	<p><u>MATERNAL EDUCATION</u> Refer to International Standard Classification of Education 1997 for more information and Kunst et al (2001).</p> <p>Assign according to the highest level of education completed (or for full-time students, level in progress).</p> <p>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 (eg. doctorates), or to other forms of higher education.</p>	<p>1 = Elementary and lower secondary 2 = Upper secondary 3 = Tertiary 9 = Not known</p>
99	SOCM	<p><u>SOCIOECONOMIC STATUS OF MOTHER</u> Current or last occupation.</p> <p>Upper non-manual – professionals, administrators and managers eg. doctor, architect, lawyer, banker, manager, teacher, nurse, performer. Lower non-manual – routine non-manual eg. Book-keeper, salesman, receptionist, secretary, computer operator, clerk, waiter. Skilled manual – cook, butcher, carpenter. Unskilled manual – semi and unskilled manual eg. factory worker, driver, agricultural worker, porter. Self employed/artisan – owner of shop, restaurant or hotel, independent artisan. Farmer – eg. self-employed farmer or fisherman.</p> <p>If code 8 ("other/student"), please specify in text in space for general comments (variable 95).</p> <p>For further information see Kunst et al (2001)*</p>	<p>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</p>
100	SOCF	<p><u>SOCIOECONOMIC STATUS OF FATHER</u> As SOCM.</p>	<p>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</p>

Sociodemographic (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code
101	MIGRANT	<p><u>MIGRANT STATUS</u></p> <p>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.</p> <p>If code 4, give text details in the general comments section (variable 95).</p>	<p>1 = Mother migrated from outside EU during pregnancy</p> <p>2 = Mother migrated from outside EU during adult life (from age 18)</p> <p>3 = Mother not a migrant as defined in 1 or 2</p> <p>4 = Other (specify in text)</p> <p>9 = Not known</p>

Footnote: *Kunst AE, Bos V, Mackenbach JP and the EU Working Group on Socio-economic Inequality in Health, "Monitoring Socio-Economic Inequalities in Health in the European Union: Guidelines and Illustrations", A Report to the Health Monitoring Programme of the European Commission.

General Comments (core variables shaded blue)

Variable Number	Variable Name	Explanation and Instructions	Code
102	GENREM	<u>GENERAL ADDITIONAL COMMENTS</u>	Free text

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