EUROCAT Guide 1.2

Instructions for the Registration of Congenital Anomalies

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WHO Collaborating Centre for the Epidemiologic Surveillance of Congenital Anomalies

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Part 1
Aim and Objectives

The aim of EUROCAT is to carry out epidemiologic surveillance of congenital anomalies in Europe

EUROCAT's objectives are:

- To provide essential epidemiologic information on congenital anomalies in Europe
- To facilitate the early warning of new teratogenic exposures
- To evaluate the effectiveness of primary prevention
- To assess the impact of developments in prenatal screening
- To act as an information and resource centre for the population and health professionals regarding clusters or exposures or risk factors of concern
- To provide a ready collaborative network and infrastructure for research related to the causes and prevention of congenital anomalies and the treatment and care of affected children
- To act as a catalyst for the setting up of registries throughout Europe collecting comparable, standardised data

Part 2

General Instructions for Data Transmission

2.1 Full members of EUROCAT transmit to the Central Registry an electronic file of individual records of all cases of congenital anomaly occurring in the population surveyed by the Register in a single year. The full dataset is given in Chapter 3. Variables not available to the register can be omitted (marked as missing) but complete information on all core variables (see 2.9) must be transmitted.

2.2 Associate members of EUROCAT transmit to the Central Registry a file of counts per anomaly subgroup, year, type of birth and maternal age. Data transmission instructions (2.5 to 2.9) are not applicable to associate members.

2.3 Full and associate members should transmit denominator information according to the template given in Part 4 of this Guide.

2.4 Guide 1.2 is a revision of Guide 1.1 which updates instructions from fixed format paper record transmission to electronic data transmission in common delimited files. Guide 1.2 is compatible with the EUROCAT Data Management Programme (EDMP V1). Problems with the interpretations of dates including the year 1999 and 2000 have been resolved and ICD10 is used in coding instructions instead of ICD9.

2.5 All data files should be validated locally first using the EUROCAT Data Management Programme (EDMP). The EDMP validates data using the validation routines specified in Part 6 of this Guide.

2.6 All data transmission to Central Registry should be files created by the EDMP for export to EUROCAT. There are two possibilities for the transmission of data to EUROCAT Central Registry:

- The EDMP is used for data entry. When your data entry is finished, run the validation and duplicate checks, make any corrections necessary, and then use the "Export" function to create a file for transmission to Central Registry.
- If you enter your data in your own local programme, you should import your data into the EDMP and run the validation routines and duplicate checks. Correct your data according to the results of these checks, import again into the EDMP and then use the "Export" function to create a file for transmission to the Central registry. This will mean that the Central registry receives standardised data in terms of formatting and

basic validation checks. You will have to import each year separately. You can then transmit each year to Central Registry in a separate file.

2.7 Instructions for the use of the EDMP are included in Part 5 of this Guide. The EDMP can be provided by Central Registry on a compact disk and will run on Access 97 and Access 2000 software.

2.8 If you are sending updated records for previous years (years already transmitted to EUROCAT Central Registry), transmit the complete set of records that year, including the updated record(s), not just the updated record(s). Central Registry will REPLACE the old file with the new file.

2.9 Core variables are the minimum EUROCAT dataset. Core variables are shaded in grey in the coding instructions (part 3 of this Guide). The EDMP will indicate as part of the validation routine where core data is missing so that you can make every effort to complete it. There is an option in the EDMP for registries that choose to transmit only core variables to Central Registry.

2.10 Some variables have been designated for local use only (L1 to L9 – see Part 3 of this Guide) and not for transmission to Central Registry.

2.11 Text variables (T1 to T21 – see Part 3 of this Guide) should be transmitted to Central Registry.

Part 3

Variables and Coding Instructions for Transmission of Data to EUROCAT Central Registry (Core variables: grey shaded)

Variable number	Variable name	Explanation and instructions	Digits	Code
1	CENTRE	Centre Number	2	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 either numbers, letters, or both. ID numbers should not repeat themselves in different years.	11	Up to 11 digits
3	NUMEURO	Sequential Number This number is automatically allocated by the EUROCAT Data Management Programme (EDMP)	4	Up to 4 digits.
4	BIRTH_DATE	Date of birth **Please enter dates as a numeric string, not in date format (eg. do not use 01/02/89 or 01-02-89, instead use 010289)**	6	Day, month, year 99 = unknown for day and month, DO NOT TRANSMIT RECORDS IF YEAR OF BIRTH IS UNKNOWN
5	PLACE	Place of birth Local code to identify institutions or other places of birth such as home delivery. Each institution should have a separate code.	5	Use local code, 99999 = not known
6	SEX	Sex Indicate chromosomal sex, if known, in case of ambiguous genitalia and code malformations in variables 47-55. 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	1 = Male 2 = Female 3 = Indeterminate 9 = Not known
7	NBRBABY	Number of babies/ fetuses delivered **Fill out a separate form for each malformed baby/fetus in a multiple set.** Record whether the twin pregnancy is monozygotic or dizygotic in the space for comments. If the co-twin is not malformed, record its sex and whether it was liveborn or stillborn in the space for comments on the form of the malformed case. 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 "syndrome" (variable 47). Give full description of type of conjoined twinning and any other malformations in space for comments and in (variables 48-55).	1	1 = Singleton 2 = Twins 3 = Triplets 4 = Quadruplets 5 = Quintuplets 6 = Sexplets + 9 = Not known

Variable Number	Variable Name	Explanation and Instructions	Digits	Code
8	BIRTHORD	Birth order in multiple set To be completed for multiple delivery only	1	1 = 1st baby delivered 2 = 2nd baby delivered 3 = 3rd baby delivered 4 = 4th baby delivered 5 = 5th baby delivered 6 = 6th+ baby delivered 9 = not known
9	NBRMALF	Number of malformed in multiple set To be completed for multiple delivery only. Complete one form for each malformed baby in a multiple set.	1	1 = one 2 = two 3 = three 4 = four 5 = five 6 = six+ 9 = not known
10	TYPE	Type of birth The distinction between livebirths, stillbirth and spontaneous abortion should follow the definitions in use in your country. There is usually a lower gestational age limit or birthweight limit for stillbirths. This varies from country to country but is usually 28 weeks, 180 days, or 500g. Below this limit fetal deaths are called spontaneous abortions. The difference between stillbirths and spontaneous abortion should follow the definitions in your country. Induced abortions 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 a spontaneous abortion or stillbirth, not an induced abortion. If an induced abortion was performed for other reasons than malformation, the case should not be transmitted to Central Registry. Early induced abortions where there was no suspicion of malformation before abortion should be excluded from the case files. Cases of any type of birth, gestational age or birthweight can be registered. Registration should concentrate particularly on all livebirths of any gestational age, all stillbirths and spontaneous abortions from 20 weeks gestation, and all induced abortions for fetal malformation of any gestational age. Make sure that both birthweight (variable 11) and gestational age (variable 12) are recorded.	1	1 = Live birth 2 = Stillbirth 3 = Spontaneous abortion 4 = Induced abortion 9 = Not known
11	WEIGHT	Birth weight Give weight in grams If less than 1,000 grams eg. 540 gm code as 0540.	4	9999 = Not known
12	GESTLENGTH	Length of gestation in completed weeks after first day of last menstrual period (LMP). **If LMP available and certain, calculate gestational age from date of LMP to date of delivery.** If LMP is available but uncertain, give the corrected gestational age by clinical ascertainment or other means. If LMP is not available, give the estimated gestational age by clinical ascertainment or other means.	2	99 =not known

Variable Number	Variable Name	Explanation and Instructions	Digits	Code
13	DEATH_DATE	Date of death **Please enter dates as a numeric string, not in date format (e.g. do not use 01/02/89 or 01-02-89, instead use 010289)**	6	day, month, year 99 = Unknown day or month NB do not use 99 for unknown year, 999999 will be read as died in 1999, day and month unknown. 555555 = Died but date completely unknown 000000 = Known to be alive 444444 or ****** = Unknown whether alive or dead (note this replaces the Guide 1.1. code 999999)
14	SURVIVAL	Survival beyond one week of age **Yes = Child known to be alive at 7 days of age.** No = Child known to be dead at or before 7 days of age (include stillbirths, abortions and neonatal deaths) Not known = Not known if child has died in the first week of life.	1	1 = Yes 2 = No 9 = Not known
15	DATEDISC	Date of discovery Date on which the baby was first suspected or recognised as being malformed, even if the detailed diagnosis is not available **Please enter dates as a numeric string, not in date format (e.g. do not use 01/02/89 or 01-02-89, instead use 010289)**	6	Day, month, year 99 = Not known for day and month 77 = Not known for year
16	WHENDISC	When discovered When the baby was first suspected to be malformed	1	1 = At birth 2 = Less than 1 week 3 = 1-4 weeks 4 = 1-12 months 5 = Over 12 months 6 = Prenatal diagnosis 7 = At abortion (spont) or termination 8 = At post mortem 9 = Not known
17	AGEDISC	If prenatally diagnosed, gestational age at discovery In completed weeks after first day of LMP. Gestational age at which the fetus was first suspected to be malformed. Indicate time of examination rather than time when result known. Give exact date in variable 15. If no prenatal diagnosis please leave blank.	2	99 = Not known
18	CONDISC	Condition at discovery Condition when malformation was first suspected	1	1 = Alive 2 = Dead 9 = Not known
19	AMNIO	Amniocentesis **"Result positive" refers to any result which indicates suspicion or diagnosis of a congenital anomaly.** "Result negative" refers to a result which does not indicate presence of a congenital anomaly, and which does not designate the case as a high risk case for further prenatal diagnostic examination. "Failed" refers to a technical failure so that there is no result.	1	1 = Performed, result positive 2 = Performed, result not known 3 = Not performed 4 = Performed, result negative 8 = Failed 9 = Not known

Variable Number	Variable Name	Explanation and Instructions	Digits	Code
20	ULTRASON	Same codes and instructions as for AMNIO (variable 19)	1	
21	CHORVILSAM	Same codes and instructions as for AMNIO (variable 19)	1	
22	OTHERTECH	Same codes and instructions as for AMNIO (variable 19). If performed, specify technique in text variable T1.	1	
23	KARYO	Karyotype of infant/fetus Specify result in text variable T2. **If performed and results known, please specify (according to Paris nomenclature).** "Failed" refers to a technical failure where a repeat examination could not be done and the karyotype is therefore unknown.	1	1 = Performed, result known 2 = Performed, result not known 3 = Not performed 8 = Failed 9 = Not known
24	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. "Result known" means that the autopsy record has been reviewed by the registry. "Result 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	1 = Performed, result known 2 = Performed, result not known 3 = Not performed 4 = Macerated fetus 9 = Not known
25	DATEMO	Date of birth of mother. 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 01/02/89 or 01-02-89, instead use 010289)**	6	Day, month, year 99 = Unknown day or month 44 or ** = Unknown year and note in comments box which code is used
26	RESIDMO	Mother's residence code Use local code for locality of residence at time of delivery		Local code
27	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.	2	99 = Not known
28	SA	Number of previous spontaneous abortions NOTE - If twin pregnancy aborted count as 2.	1	0 = None 1 = One 2 = Two 3 = Three etc. 8 = Eight+ 9 = Not known
29	IA	Number of previous induced abortions NOTE - If twin pregnancy aborted count as 2, unless selective induced abortion was performed.	1	0 = None 1 = One 2 = Two 3 = Three etc. 8 = Eight+ 9 = Not known

Variable Number	Variable Name	Explanation and Instructions	Digits	Code
30	LB	Number of previous live births NOTE - If twin pregnancy count as 2 if both liveborn.	2	00 = None 01 = One 02 = Two 03 = Three etc. 20 = Twenty+ 99 = Not known
31	SB	Number of previous stillbirths NOTE - If twin pregnancy count as 2 if both stillborn.	1	0 = None 1 = One 2 = Two 3 = Three etc. 8 = Eight+ 9 = Not known
32	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.	2	00 = None 01 = One 02 = Two 03 = Three etc. 20 = Twenty+ 99 = Not known
33	OCCUPMO	Mother's occupation Code main occupation at time of conception Code according to the 1988 International Standard Classification of Occupation (ISCO) – 4 digits. http://www.ilo.org/public/english/bureau/stat/res/isco.htm. More detail in book: International Standard Classification of Occupations, ISCO-88. International Labour Office, Geneva, 1990. EUROCAT supplement for other categories: 99099 Worker 99199 Labourer 99299 Skilled worker 99399 Student 99499 Housewife 99599 Unemployed 99699 Army 99799 Civil servant 99999 Unknown	5	If 4th or 5th digit not used please leave blank
34	ASSCONCEPT	Assisted conception IVF = In vitro fertilisation GIFT = Gamete intra fallopian transfer	1	0 = No 1 = Induced ovulation only 2 = Artificial insemination 3 = IVF 4 = GIFT 8 = Other 9 = Not known
35	ILLBEF	Illness before pregnancy Record any illness whether chronic or acute with onset before pregnancy and that may adversely affect fetal development (eg. childhood cancer, metabolic disease). Any additional details may be entered in text variable T12 GENREM. Abridged List: Hyperthyroidism E05.0 – E05.9 Hypothyrodism E00.0 – E03.9 Diabetes Melitus E14.0 – E14.9 Obesity E66.0 – E66.9 Epilepsy G40.0 – G40.9 Asthma J45.0 – J45.9	4	ICD10 0000 = No 0001 = Yes, but no information available 9999 = Not known

Variable Number	Variable Name	Explanation and Instructions	Digits	Code
36	ILLDUR1	Illness during pregnancy Record any illness whether chronic or acute with onset during pregnancy. Asymptomatic maternal infection should be recorded. Any additional details may be entered in text variable T12 GENREM. Abridged List: Eclampsia O15.0 - O15.9 Hypertension During Pregnancy O16.0 - O16.9 Diabetes Melitus During Pregnancy O24.0 - O24.9 Abnormal Glucose Tolerance O24.0 - O24.9 Anaemia O99.0 For maternal infections, use chapters A and B of the ICD10 coding (4 digits). Foetal infections and associated malformations should be coded under syndrome and malformation 1-8 codes (variable 48-55). Coxackie B34.1 Cytomegalic Inclusion Diseases B25.0 - B25.9 Herpes Simplex B00.0 - B00.9 HIV (AIDS) B20.0 - B24.9 Influenza J10.0 - J11.9 Listeria A32.0 - A32.9 Mumps B26.0 - B26.9 Rubella B06.0 - B06.9 Syphilis A53.0 - A53.9 Toxoplasmosis B58.0 - B58.9 Varicella (Chicken Pox) B01.0 - B01.9 Viral Hepatitis B19.0 - B19.9	4	ICD10 0000 = No 0001 = Yes, but no information available 9999 = Not known
37	ILLDUR2	As for ILLDUR1 Any additional details may be entered in text variable T12 GENREM.	4	As for ILLDUR1
38	HABIT1	Habitual exposures Record any habitual exposures that may adversely affect the pregnancy (eg. smoking, drinking alcohol, drug use etc.) Please give details in text variable T3 SP_HABIT1.	4	ICD10 0000 = No 0001 = Yes, but no information available 9999 = Unknown
39	HABIT2	As for HABIT1 Please give details in text variable T4 SP_HABIT2.	4	As for HABIT1
40	UNUSEXP	Unusual exposures Record any unusual exposures that may adversely affect the pregnancy (eg. car accident, carbon monoxide, intoxication, poisoning etc.) Please give details in text variable T5 SP_UNUSEX.	4	ICD10 0000 = No 0001 = Yes, but no information available 9999 = Unknown

Variable Number	Variable Name	Explanation and Instructions	Digits	Code
41	DRUGS1	Drugs 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 (ie. etretinate). 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. Do not record usual vitamins and minerals supplementation, but record unusual intakes of vitamins or minerals (eg. Vitamin A megadoses). Record the proprietary name (trademark) preferably. Details on the dosage and timing are to be recoded at local level but not transmitted routinely to Central Registry. Do not forget to mention in the appropriate section (disease during or before pregnancy) the indication for drug use. Advice from a physician or pharmacist may be useful for assigning a drug to a specific class. Details may be found in "Goodman and Gilman's, The Pharmacological Basis of Therapeutics, MacMillan Publishing Company, New York, 1985". Only drugs taken at physiologic doses to be recorded. Drug overdoses or self poisoning should be recorded under 'Unusual exposure' (variable 40). Please give details in text variable T6 SP_DRUGS1.	2	00 = No drugs 01 = Atropinics and antispasmodics 02 = Anaesthetics, local and general 03 = Hypnotics, sedatives and psychotropics 04 = Antiepileptics 05 = Analgesics, antipyretics and antiinflammatory agents 06 = Histamine antagonists 07 = Antiashthmatic agents including methylxanthines 08 = Antiarhythmic and antihypertensive agents 09 = Diuretics 10 = Tocolytics 11 = Antiseptics, antibiotics, antiviral, antiparasitic and antifungal agents 12 = Antiproliferative and immunosuppressive agents 13 = Anticoagulant, antithrombotic and thrombolytic drugs 14 = Thyroid and antithyroid drugs 15 = Oestrogens, progestins and androgens, including oral contraceptives 16 = Adrenocortical steroids 17 = Insulin and oral hypoglycemic agents 18 = Vaccines 19 = Vitamins and minerals 88 = Other 98 = Drug(s) taken but no information available 99 = Not known
42	DRUGS2	As for DRUGS1 Please give details in text variable T7 SP_DRUGS2.	2	As for DRUGS1
43	DRUGS3	As for DRUGS1 Please give details in text variable T8 SP_DRUGS3.	2	As for DRUGS1
44	DATEFA	Date of birth of father. Give as much information as is known eg: Feb 1963 = 990263 1963 = 999963 **Please enter dates as a numeric string, not in date format (e.g. do not use 01/02/63 or 01-02-63, instead use 010263)**	6	Day, month, year 99 = Unknown day or month 44 or ** = Unknown year and note in comments box which code is used
45	AGEFA	Age of father at delivery In completed years at time of delivery	2	99 = Not known
46	OCCUPFA	Occupation of father	5	99999 = Unknown 88999 = If single mother, father's occupation unknown All other codes see OCCUPMO (variable 33)

Variable Number	Variable Name	Explanation and Instructions	Digits	Code
47	SYNDROME	Syndrome Give name of syndromes, associations and diseases in text variable T13. If not a recognisable syndrome, eponym or disease, leave blank If a recognisable syndrome, eponym or disease with no specified code, then code 88888 and specify name in writing. All the anomalies observed by the local clinician should be coded in the remaining boxes for malformations. When 2 syndromes are present in the same subject, code the more important one in the syndrome variable 47 and T13, and include the other one in variable 48 and T14 MALF01. Ensure karyotype information is given in text variable T2, and that autopsy and medical genetics reports have been reviewed, where appropriate. In case of conjoined twins, give full description in syndrome text variable T13.	7	ICD 10 First 4 digits are ICD10 5th digit = BPA supplement or leave blank
48	MALFO1	Malformation A list of minor exclusions is given in EUROCAT Guide 1.2, section 7. Only a baby/fetus with minor anomalies and no major anomalies should be excluded. When a major anomaly is present, code both major and minor anomalies. 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 T21 SP_MALF08). Include in the 8 specified codes the most important ones, or those tabulated in EUROCAT Reports. Give in the fullest description of the malformations available in malformation text variables T14-T21.	5	ICD 10 First 4 digits are ICD 5th digit= BPA classification OR leave blank
49	MALFO2	As MALF01	5	As MALF01
50	MALFO3	As MALF01	5	As MALF01
51	MALFO4	As MALF01	5	As MALF01
52	MALFO5	As MALF01	5	As MALF01
53	MALFO6	As MALF01	5	As MALF01
54	MALFO7	As MALF01	5	As MALF01
55	MALFO8	As MALF01	5	As MALF01
56	MCKUSICK	McKusick Code / Type of Mendelian Inheritance This code is to be used for conditions with single gene origin only. The first digit may be filled in without the rest of the code if the full McKusick code is unknown. Full codes can be found on the OMIM website: **http://www3.ncbi.nlm.nih.gov/Omim/**	5	First digit designates mode of inheritance: 1 = Autosomal dominant 2 = Autosomal recessive 3 = X-linked

Variable Number	Variable Name	Explanation and Instructions	Digits	Code
57	MODETRANS	Mode of transmission For single gene or chromosomal origin, code whether in this particular baby/fetus, the mutation was carried in the somatic cells of one (both) parent(s) or whether it is a de novo event	1	1 = Familial 2 = De Novo 9 = Not known
58	CONSANG	Consanguinity 1st degree = sib or parent 2nd degree = uncle, aunt, grandparent 1st cousin once removed = the child of a first cousin 2nd cousin = child of the parent's first cousin If other relation, specify.	1	0 = Not related 1 = 1st degree 2 = 2nd degree 3 = 1st cousin 4 = 1st cousin once removed 5 = 2nd cousin 8 = Other relation 9 = Not known
59	PREVSIB	Previous sibs notified to EUROCAT If yes, give the local code in variable SIB1, SIB2 or SIB3 (variables 60-62). Include malformed co-twins or sibs from the same pregnancy, irrespective of birth order within multiple set Exclude conjoined twin.	1	1 = Yes 2 = No 9 = Not known
60	SIB1	Local ID number notified to the Central Registry Enter here also the code numbers of co-twins or sibs from the same pregnancy, irrespective of birth order within multiple set. Leave blank if no previous sibs notified to EUROCAT.	11	Local ID
61	SIB2	As SIB1	11	Local ID
62	SIB3	As SIB1	11	Local ID
63	SIBANOM	Sibs with anomalies Specify type of anomaly and describe the malformation for each sib. If one sib has both the same anomaly and a different anomaly, code under ‘same’. If one sib has both the same anomaly and a different sib has another anomaly, code under ‘same and other’. Please give details in text variable T9 SP_SIBANOM.	1	1 = Same 2 = Other 3 = Same and other 4 = No 0 or 9 = Not known

Variable Number	Variable Name	Explanation and Instructions	Digits	Code
64	MOANOM	Mother's family with anomalies Include mother herself as well as mother's family. Specify type of anomaly 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. If the aetiology is unknown or multifactorial, 'same' is a matter of judgement 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 one relative has both the same and another anomaly, code 'same'. Restrict the family to first, second and third degree relatives (mother, father, sibs, grandparents, aunts, uncles, half-sibs, first cousins). Please give details in text variable T10 SP_MOANOM.	1	1 = Same 2 = Other 3 = Same and other 4 = No 0 or 9 = Not known
65	FAANOM	As MOANOM Please give details in text variable T11 SP_FAANOM.	1	As MOANOM

Variable Number	Variable Name	Explanation and Instructions	Digits	Code
LOCAL Variables				
L1		**Date of Last Menstrual Period** **Please enter dates as a numeric string, not in date format (e.g. do not use 01/02/63 or 01-02-63, instead use 010263)**	6	Day, month, year 999999 = Not known 000000 = No LMP
L2		**Certainty of Last Menstrual Period**	1	1 = Certain 2 = Uncertain 3 = No LMP 4 = Not known
L3		**Sources of Information**	5	1 = Notes in routine scan 2 = Birth notification or notification of malformation at birth 3 = Hospital case notes 4 = Death or stillbirth certificate 5 = Prenatal diagnosis 6 = Laboratory report (cytogenetic, chemical etc.) 7 = Post mortem examination 8 = Other 9 = Not known
L4		**Social Status Mother**	1	
L5		**Racial Type Mother**	1	
L6		**Social Status Father**	1	
L7		**Racial Type Father**	1	
L8		**Chronic Illness Father** See “illness before pregnancy” under mother (variable 35).	4	
L9		**Confirmation of Diagnosis**	1	1 = Confirmed 2 = Follow-up needed for confirmation 3 = Not confirmed, but infant lost to follow-up 4 = Not known

Variable Number	Variable Name	Explanation and Instructions	Digits	Code
Text variables		Please place after numerical variables or in separate file		
T1	SP_OTECH	Specify other technique for prenatal diagnosis (see OTHERTECH, variable 22)		
T2	SP_KARYO	Specify karyotype		
T3	SP_HABIT1	Specify habitual exposures		
T4	SP_HABIT2	Specify habitual exposures		
T5	SP_UNUSEXP	Specify unusual exposures		
T6	SP_DRUGS1	Specify drug exposures		
T7	SP_DRUGS2	Specify drug exposures		
T8	SP_DRUGS3	Specify drug exposures		
T9	SP_SIBANOM	Specify type of anomaly and describe the malformation		
T10	SP_MOANOM	Specify type of anomaly and describe the malformation		
T11	SP_FAANOM	Specify type of anomaly and describe the malformation		
T12	GENREM	General additional comments		
T13	SP_SYNDROM	Specify syndrome		
T14	SP_MALFO1	Specify malformation		
T15	SP_MALFO2	Specify malformation		
T16	SP_MALFO3	Specify malformation		
T17	SP_MALFO4	Specify malformation		
T18	SP_MALFO5	Specify malformation		
T19	SP_MALFO6	Specify malformation		
T20	SP_MALFO7	Specify malformation		
T21	SP_MALFO8	Specify malformation		

Part 4
Template for Denominator Data

Please complete the attached table or ask Barbara Norton (eurocat@ulst.ac.uk) for this template in computerised form. Please send denominator data with every new year of case data.

Centre :					
Year					
Live births					
Still-Births					
Total					
Please give definition of stillbirths:					
Age distribution:					
Mother <20					
Mother 20 - 24					
Mother 25 - 29					
Mother 30 - 34					
Mother 35 - 39					
Mother 40 – 44 *					
Mother 45+					
Unknown					
Total **					
*** Does age group 40-44 include births in mothers aged 45 and over ? (please delete as appropriate) YES/NO** **** Are stillbirths included in the maternal age distribution ? (please delete as appropriate) YES/NO**					
Monthly distribution:					
January					
February					
March					
April					
May					
June					
July					
August					
September					
October					
November					
December					
Total *					
*** Are stillbirths included in the distribution by month (please delete as appropriate) YES/NO**					

Part 5
Data Management Programme (EDMP) Instructions

5.1 Introduction

The EUROCAT Data Management Program (EDMP) has been designed as a flexible tool to assist you in the collection, management, reporting and analysis of congenital anomaly data.

Please take note of the backing up details given below in section 5.3.

5.2 System Requirements and Program Details

The EDMP database has been written in Microsoft Access and will therefore only run on PCs which have either Access 97 or Access 2000 installed. It is not possible to run the EDMP database using earlier versions of Access (e.g. Access versions 1, 2 or 95). The program will automatically scale itself to fit any screen resolution from 800x600 up to1280x1024.

The program is comprised of two database files, one to store the data (Edmpdata.mdb) and the other to provide the user interface (edmp.mde). You can use the EDMP program on single or networked PC.

5.3 Backup

You need to make regular backups of your data, ideally you should create a new backup at the end of each day that you have used the EDMP program. Remember to keep a recent backup at a different location to your PC in order to guard against fire or theft.

The data file you need to backup on a regular basis is Edmpdata.mdb. The option 'Data Location' available from the system menu will tell you where this file is on your PC or network. There are many methods and programs available to create your backups. Windows 95, 98 and NT provide backup utilities (Microsoft Backup) which can be used if you do not have access to any other third party backup utility. Microsoft Backup is not always installed on initial Windows set-up but can be installed using the add/remove programs option under the settings menu.

5.4 Getting started

5.4.1 Installation

The EDMP program will be provided on a compact disk (CD) which contains versions for Access 97 and Access 2000. The versions are contained in separate folders on the CD (namely Access97 and Access2000). Installation instructions are also on the CD in the file Install.txt. To install the EDMP program follow the instructions below.

a) Create a new folder on your hard drive using windows explorer or My computer. In this example we are using the folder called Edmp (C:\Edmp).

Access 97 only

b) Copy the files Edmp.mdb and Edmpdata.mdb from the Access97 folder on the CD to the newly created directory.

Access 2000 only

b) Copy the files Edmp.mdb and Edmpdata.mdb from the Access2000 folder on the CD to the newly created directory.

c) When Edmp.mde and Edmpdata.mdb have been copied from the CD you will need to right click on them, select properties and uncheck the read-only attribute.

d) Create a shortcut by right clicking on Edmp.mde in windows explorer or My computer and then selecting 'create shortcut'. Drag and drop the shortcut onto your desktop.

Network installation

If you wish to install the EDMP program on a network then all you need to do is to follow the next two steps.

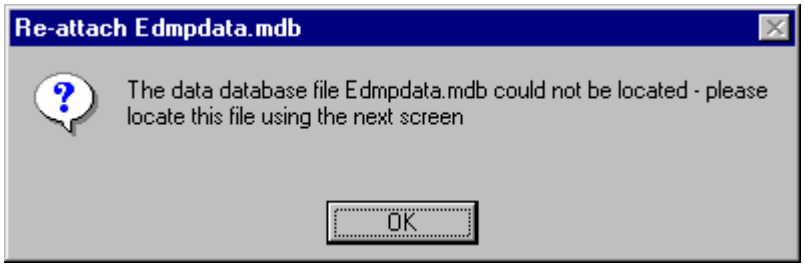
1) Move Edmpdata.mdb into a shared directory on the server and set any permissions as necessary.
2) Copy Edmp.mde onto each PC that will be running the program. Do not run Edmp.mde from the shared server directory, as there are a number of runtime processes that are individual to each session and are not suitable for sharing.

Although the EDMP program is network enabled it is not a true client/server version and will not provide satisfactory response times when used with dial-up remote access.

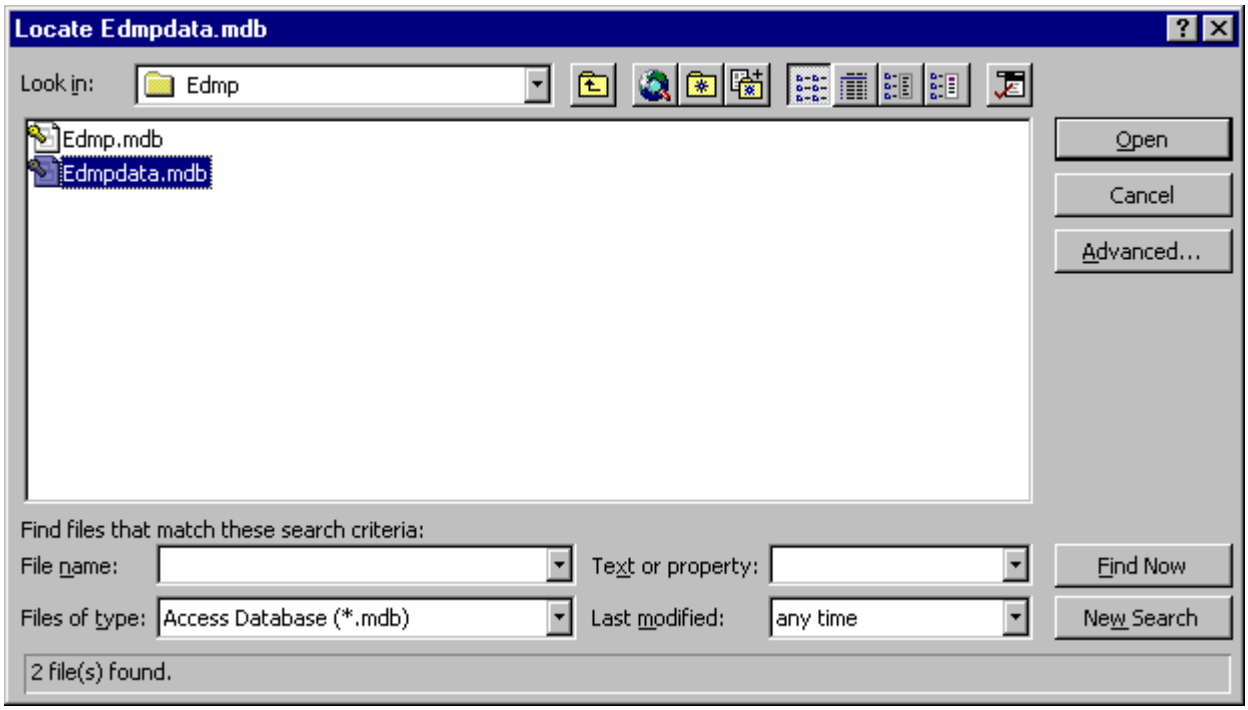
5.4.2 First Time Use

Logging into the EDMP program is normally a simple affair of typing in your username and password. However, the first time you run the program you may be prompted to locate Edmpdata.mdb (where the data is stored), specify your centre name and select the default printer.

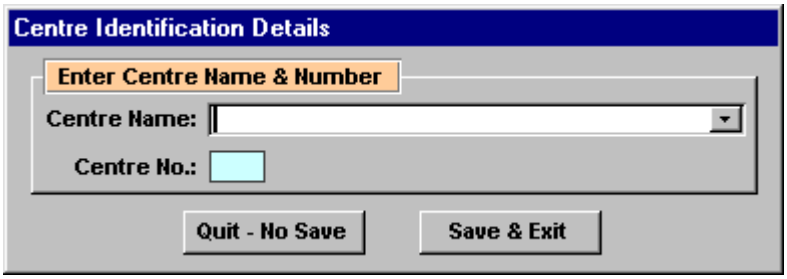
Each time you run the EDMP the first thing it does is to check to see that the program can locate the data file Edmpdata.mdb. If Edmpdata.mdb is not where it thinks it should be (i.e. after installation or if it has been moved to a different folder) then the following message will be displayed.



When you click on OK the following file selection screen will appear from which you select the folder and file (Edmpdata.mdb) in the usual Windows fashion and then click on the 'Open' button.



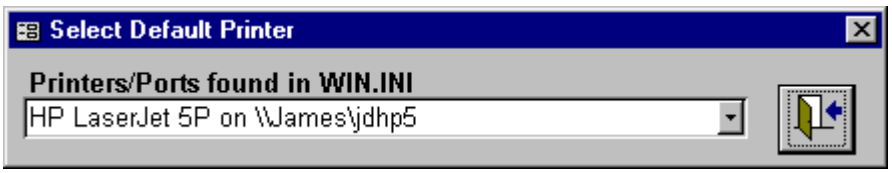
Once EDMP is happy that the data database has been located then you will need to select your centre from the list using the screen below.



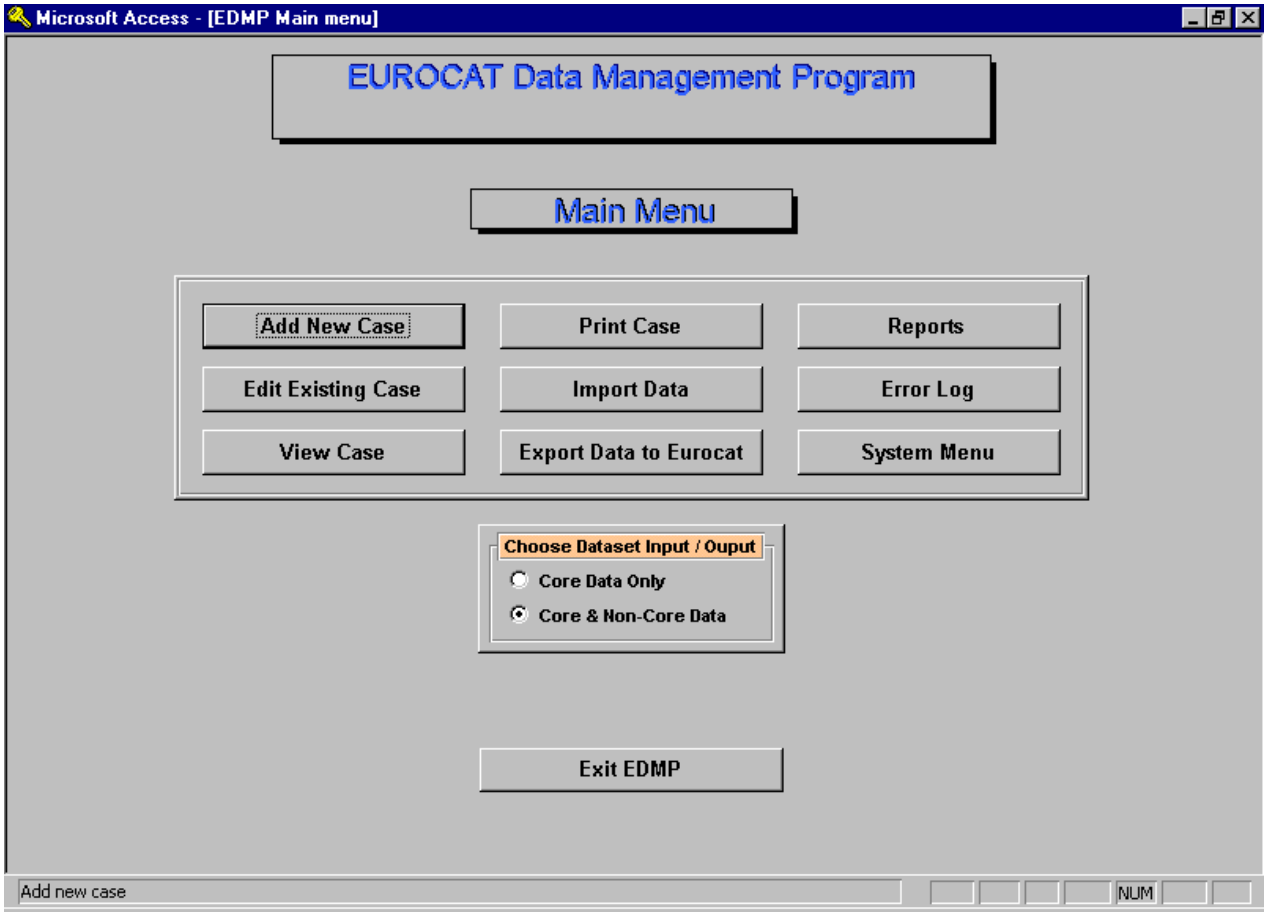
Once you have selected your centre the login screen will be displayed. To login all you need to do is enter your username and password at the prompts provided. The program comes with the username ‘m’ and password ‘m’ already available. Please note that one of the first things that you should do is to add your own username and password and remove the installation defaults of ‘m’ and ‘m’ using the Users & Passwords facility under the System Menu (see below).

Normally the main menu is displayed after you have logged in successfully. However, sometimes (and usually after installation) the following message is displayed and this indicates that the default Windows printer has changed since the last time the program was run.

When this screen appears click on OK and then select the printer you require from the pull down list on the next screen. Once you have selected the required printer click on the exit button (button with door and arrow icon). All the printers, including network printers, that are available to your PC will be displayed in the pull down list.



After you have logged in the main menu will be displayed.



5.5 Main menu

The main menu offers you the following choices.

Choose Dataset Input / Output

There are two options for dataset input / output: 'Core Data Only' and 'Core & Non-Core Data'. When the 'Core Data Only' option is selected the data for adding, editing, viewing, printing and exporting is restricted to the core variables only. The program will remember the preferred option setting for each individual user.

Add New Case

This facility allows you to add new cases. You can also check for possible duplicate matches against existing records and also run validation checks on the data.

Edit Existing Case

Edit case allows you to add further data to existing records and alter incorrect information. Also you can check for possible duplicate matches and run validation checks on the data.
After you have selected the required case from a list of cases, specified by criteria, you can navigate through the data making changes and additions as necessary.

View Existing Case

View existing case just allows you to view case details, no editing, additions, duplicate checks or data validation can take place.

Print Case

This provides a print out of an entire case where the amount of data printed is based on the current dataset input / output option. All printouts and reports are displayed on the screen in preview mode. You can send the preview to the printer by clicking on the printer icon: 

Alternatively you can send the report to Word, Excel or Notepad by clicking on the Office Links button: 

Import Data

Import data allows for the import of data from a comma separated variable (.csv) file. Variables whose name match those specified in the EUROCAT Central Registry Data Transmission Form will be imported whilst other variables will be ignored.

Export Data

Export data allows for the export of chosen cases into a comma separated variable (.csv) file.

Reports

The reports facility allows you to print a variety of reports summarising your data. You can also enter selection criteria to create subsets of data to report on and in this way you can perform comparisons within your data.

Error Log

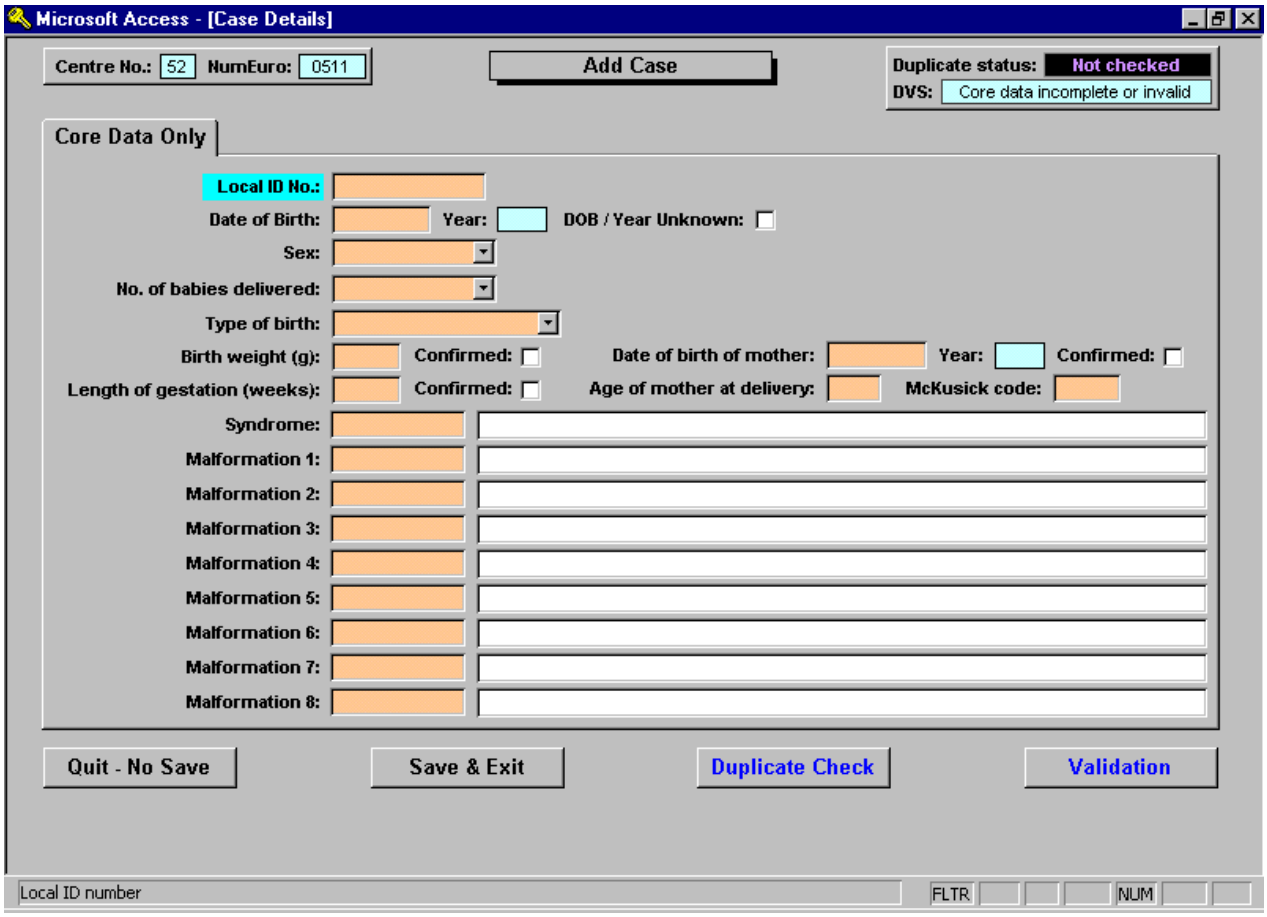
The error log facility allows the printing of errors associated with a case or cases to be printed out. The cases to be checked for errors can be specified by entering criteria about them.

System Menu

The system menu provides you with the facility to add and alter users and passwords, set the default printer, delete cases, see the location of the data and enter your centre name and number.

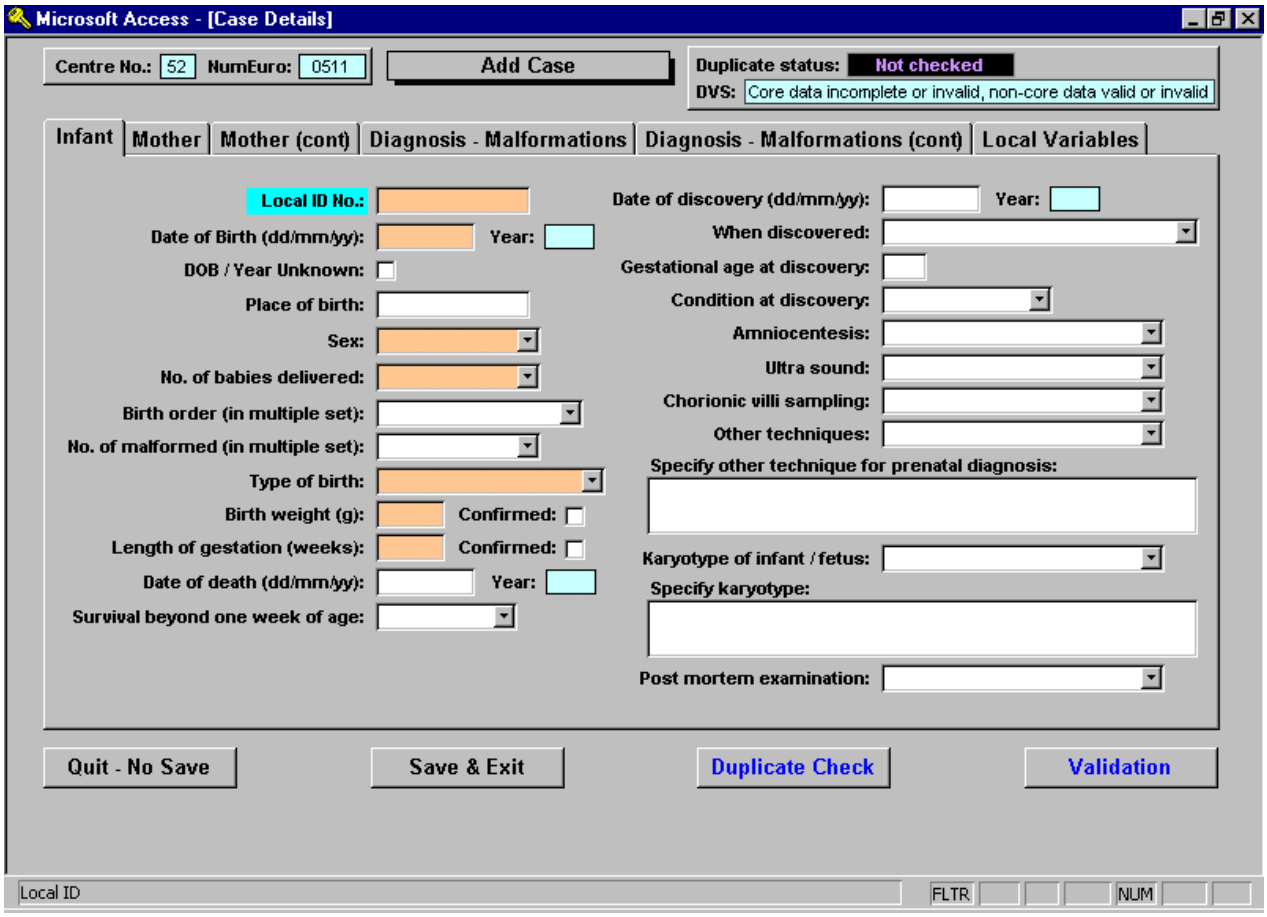
5.6 Add / Edit Case

The dataset option chosen on the main menu dictates how the 'Add New Case' form will look. If core data only was selected then the screen shown below will be displayed allowing for the entry of core data only.



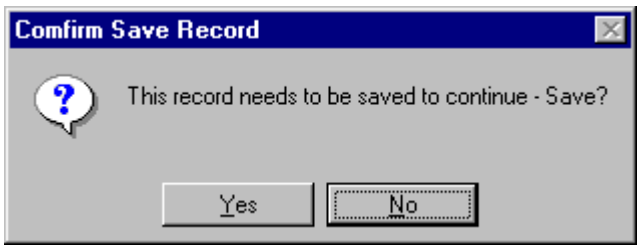
When the core and non-core option is checked then the 'Add New Case' form changes to the one shown below to allow for the entry of non-core data as well. You

navigate through the ‘pages’ of data by clicking on the relevant tab i.e. ‘Infant’, ‘Mother’ etc. This is also the same when editing or viewing a case. When viewing a case you cannot make changes to it, check for duplicates or do validation checking. Core data field backgrounds are highlighted in orange to make them easily identifiable. The last page ‘Local Variables’ provides a number of fields that are for local use only and are not exported under the ‘Export Data To EUROCAT’ facility. It also includes five spare variable which you can rename to suit your own use.



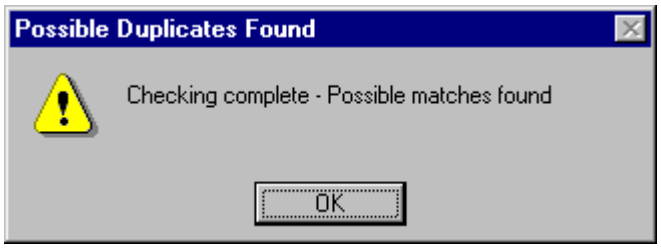
5.6.1 Duplicate Checking

The ‘Duplicate check’ button when clicked checks for possible matches of other cases against the case you are currently adding or editing. You will be asked to save the record first as shown here:

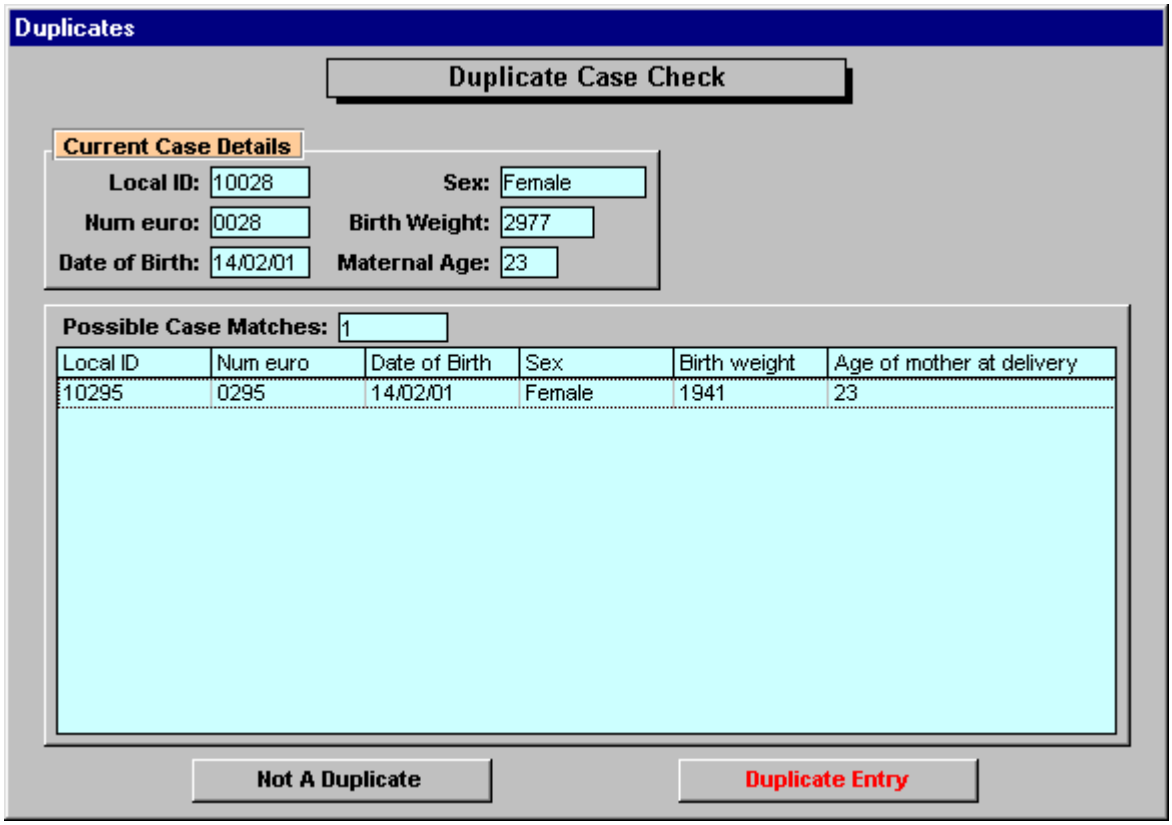


Clicking the ‘Yes’ Button then allows the checking to take place.

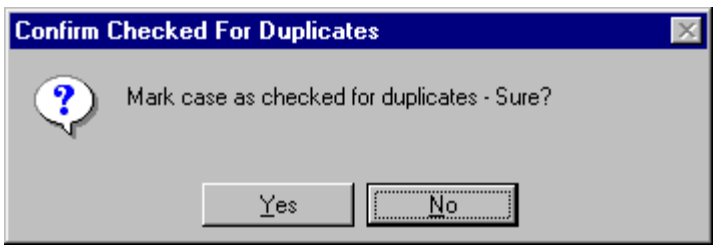
Once checking is completed if any matches are found a screen will pop up informing you that possible matches were found.



When you click the ‘Ok’ button a screen will be displayed showing the possible matches against the current case.

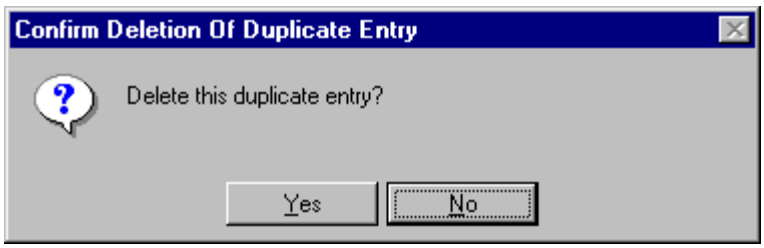


The screen above shows the current case at the top and then list’s out the possible matches in the box below. As you can see from the above example there one possible match against the case, but it is not a match you would click the ‘Not a duplicate’ button. You would then be asked the following:



Hitting the ‘Yes’ button would mark the case as being checked for duplicates(no matches found).

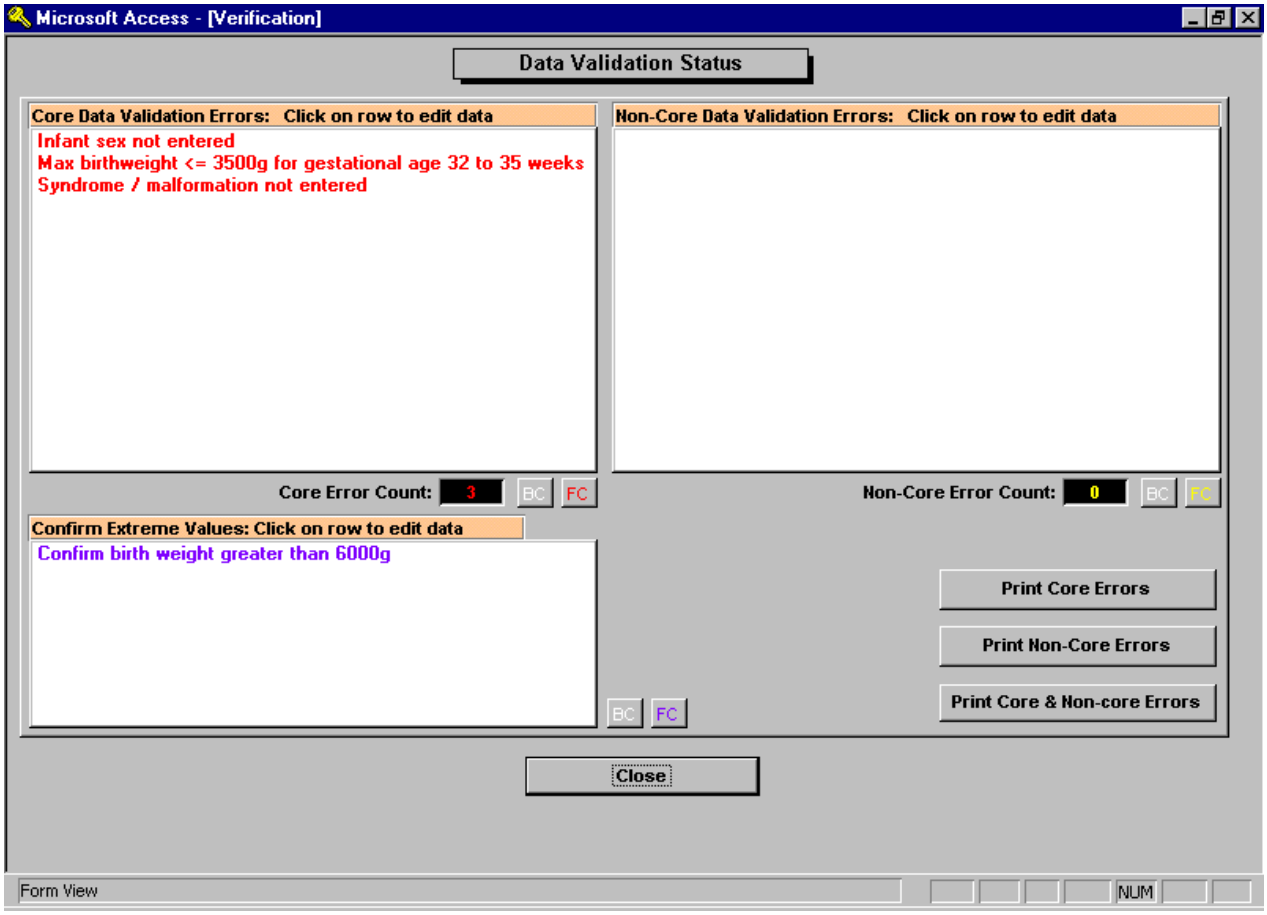
If you had clicked on the ‘Duplicate Entry’ Button then you would have been asked the following:



By hitting the ‘Yes’ button you would be confirming the deletion of the duplicate record.

5.6.2 Validation

Validation of the data runs checks on the data checking for possible errors.

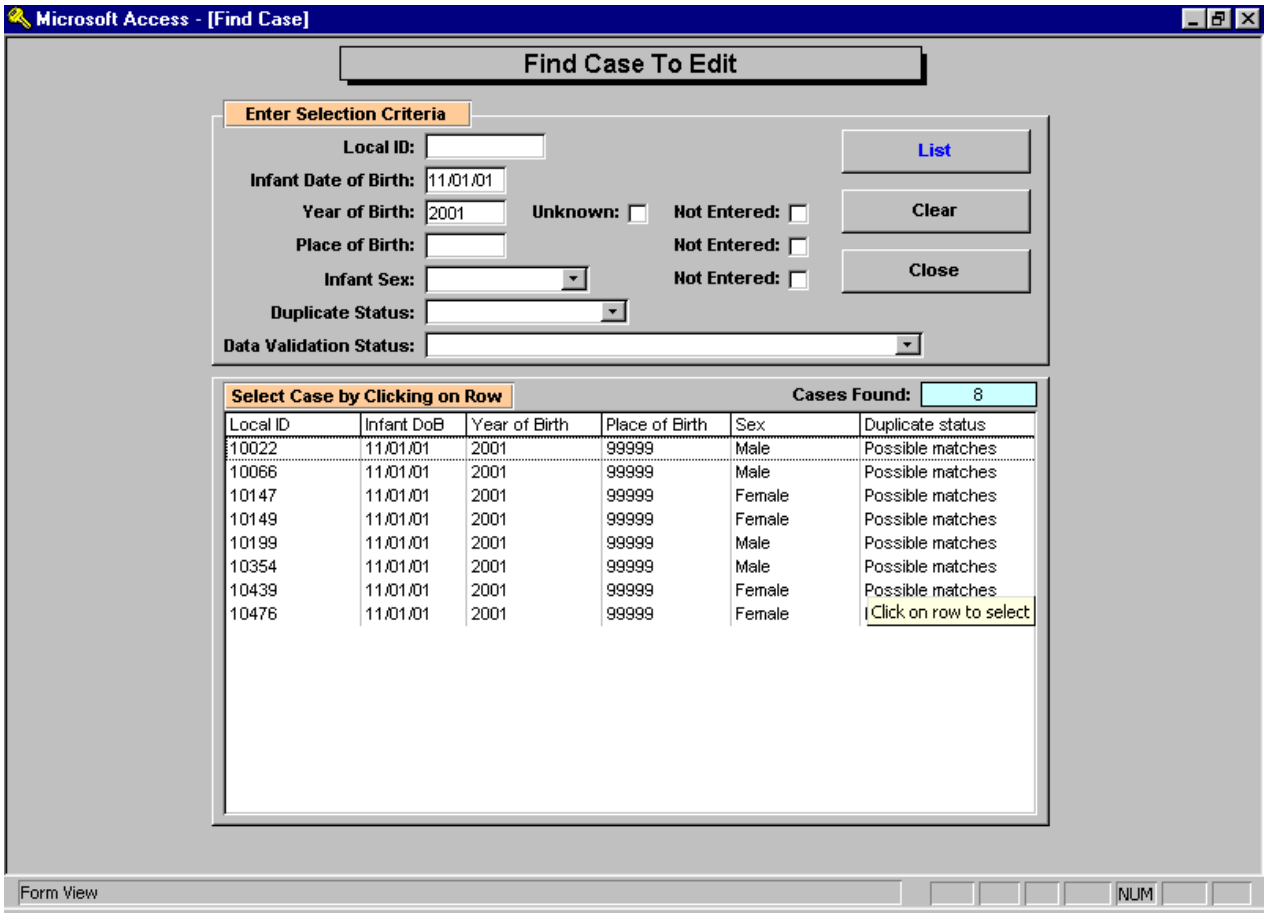


The screen above shows the data validation status (DVS) of a case. As you can see from the above example core data errors are shown in the top left box, non-core in

the top right box and extreme value errors in the bottom left box. To go straight to the error just click on the relevant row. From this screen you also have the option to printout the errors for core and non-core data for that case. For extreme values there is a tick box by the relevant field to confirm that the value entered is correct. Once extreme values have been confirmed they will no longer be displayed as extreme at data validation.

5.6.3 Edit

To edit an existing case you firstly need to locate the case using the 'Find Case' screen shown below:



The find case form is very easy to use. All you have to do is to enter any required selection criteria and then click on the 'List' button. Matching cases will be displayed in the list box and to edit a case simply click on the required row. In the example above Eight cases match the selection criteria of Infant DoB = 11/01/01.

5.7 Import Data

You can use the import facility to enter a batch of cases from file, rather than entering them via the screen. Typically you would import cases if you were

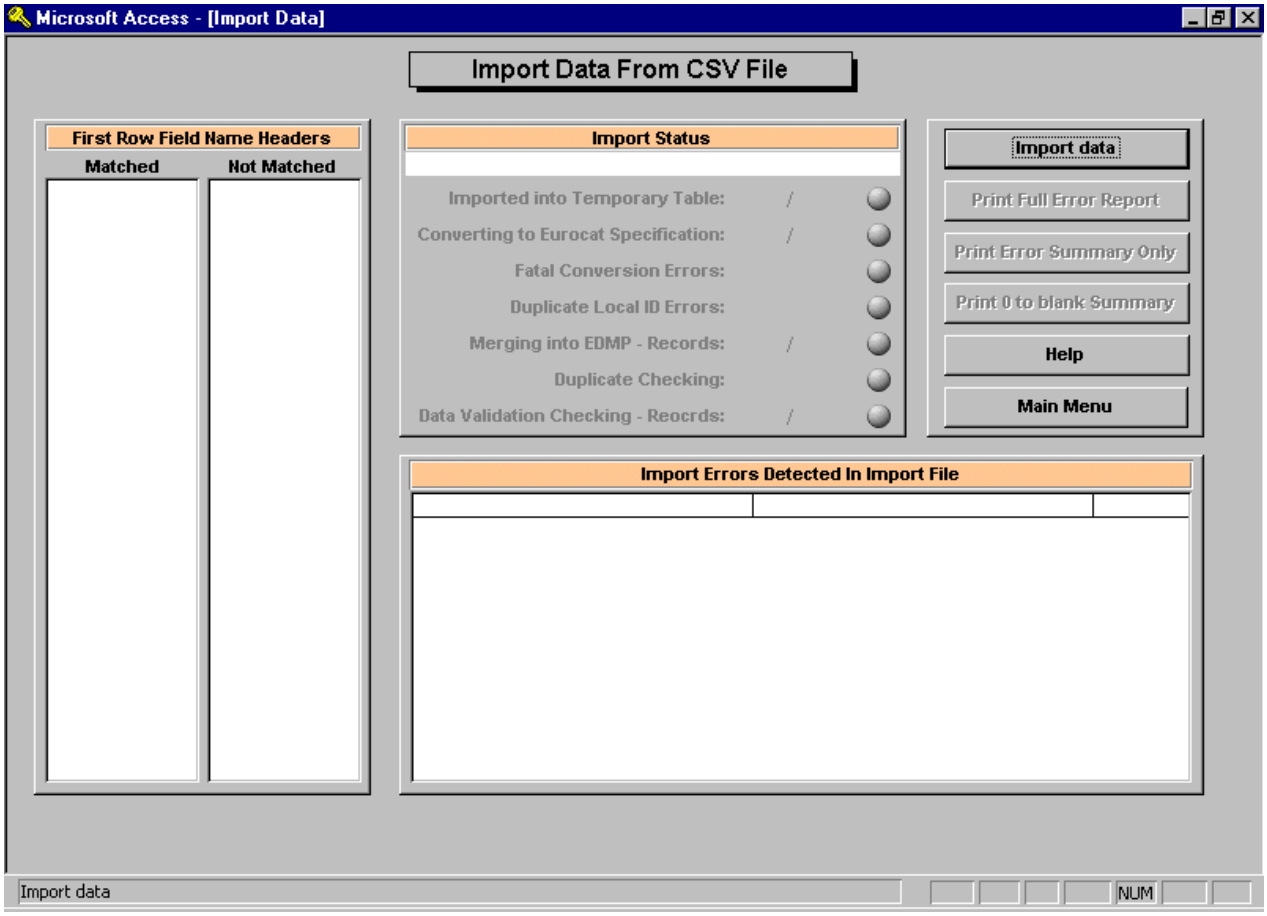
converting to EDMP from a different data entry program or if you are using EDMP to validate your own data prior to transmission to the Central Registry.

For a file to be imported successfully it must fulfil the following criteria:

1) The file must be in comma separated format (.csv)
2) The field names must be in the first row of the data
3) One of the field names must be 'centre' which is your EUROCAT centre number.
4) The centre number must be present in every row of the data.
5) Date fields must be in the format specified in the Data Transmission Form i.e. 6 characters wide and must include any leading zeros. For example the 7th May 2001 would be 070501. However, EDMP will try and read date fields that have lost their leading '0' and are only 5 characters long and the dates will be accepted if they convert to a valid date.
6) Coded variables must conform to values specified in 'EUROCAT Data Transmission Form' with the exception that '0' entries for coded fields will be converted to blanks where '0' is not a valid entry.
7) Blank lines must be removed from the data including trailing carriage returns and line feeds.

If you are creating your import file using Excel the date fields will need to be formatted to ensure that the leading zeros are not removed from the .csv file. Use 'Text' or 'Custom' formats for these date fields, if you choose custom then specify 000000 as the format (six zeros).

To import a .csv file click on the 'Import data' button as shown below:



You will then be prompted for the location of the file using the standard Windows file location screen. Once found the program will try to import the file. The status of the import as it goes through various stages is also shown. The Stages of import are as follows:

Import Record

This is the import of the raw data from the import csv file into a temporary table within the EDMP. The variables whose name matches those specified in the Data Transmission Form will be listed in 'Matched' box and those which do not match will be listed in the 'Not Matched' box. If any errors are encountered during import they will be listed in the 'Import Errors Detected In Import File' box. Access has been unable to import these rows and indicates serious data problems that need to be corrected in the raw data prior to import.

Converted Records

The data in the imported records are then converted into EDMP format.

Fatal Conversion Errors

If any fatal conversion errors are found the import process will be stopped and corrections need to be applied to the original data or the csv file.

Duplicate Local ID Errors
If any records within the import file contain the same local ID numbers that are already in the EDMP then again the process will be stopped.

Merged Records
Once checks are completed and passed the records will be merged into EDMP.

Duplicate Checking
Duplicate checking will then be performed on the newly imported records and each record will be marked with its matching status (Checked / Possible matches).

Data Validation Checking
The records will then be validated and given a data validation status. Which are as follows:
1) Core data incomplete or invalid, non-core data valid or invalid
2) Core data complete & valid, non-core data invalid
3) Core data complete & valid, non-core data valid

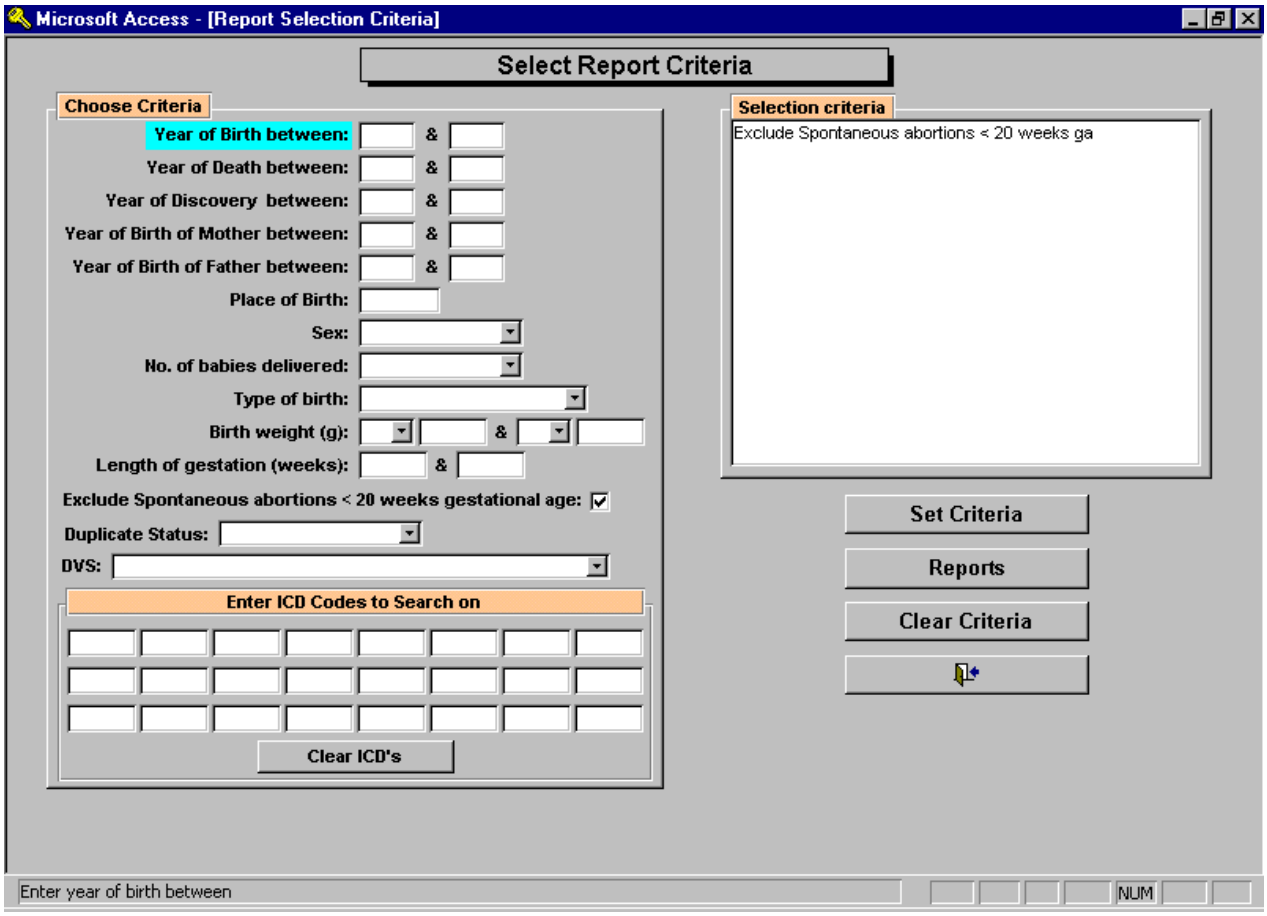
Once the import has stopped you can print an error report for any errors found (Summary, Full or '0' to blank conversions).

5.8 Export Data To EUROCAT

When sending data to the Central Registry you need to send the data for each year in a separate file. To export data simply select the required year from the screen shown below and click on the 'Export Cases' button. You will need to specify the name and location of the export csv file in the usual manner. You can export either Core or Core & Non-core data depending upon the data input/output setting on the main menu. You can export different selections of data (i.e. wider year ranges) under the reports section.

5.9 Reports (by Selection Criteria)

This option provides you with a simple and powerful way to analyse and describe your data. It does this by providing you with a selection criteria screen. Once you have entered your selection criteria, if any, you can then run the standard reports on that subset of data. You analyse your data by comparing the reports for different selection criteria. For instance you can compare the numbers of males and female infants by listing the data after selecting males and again after selecting females. The selection screen is shown below:

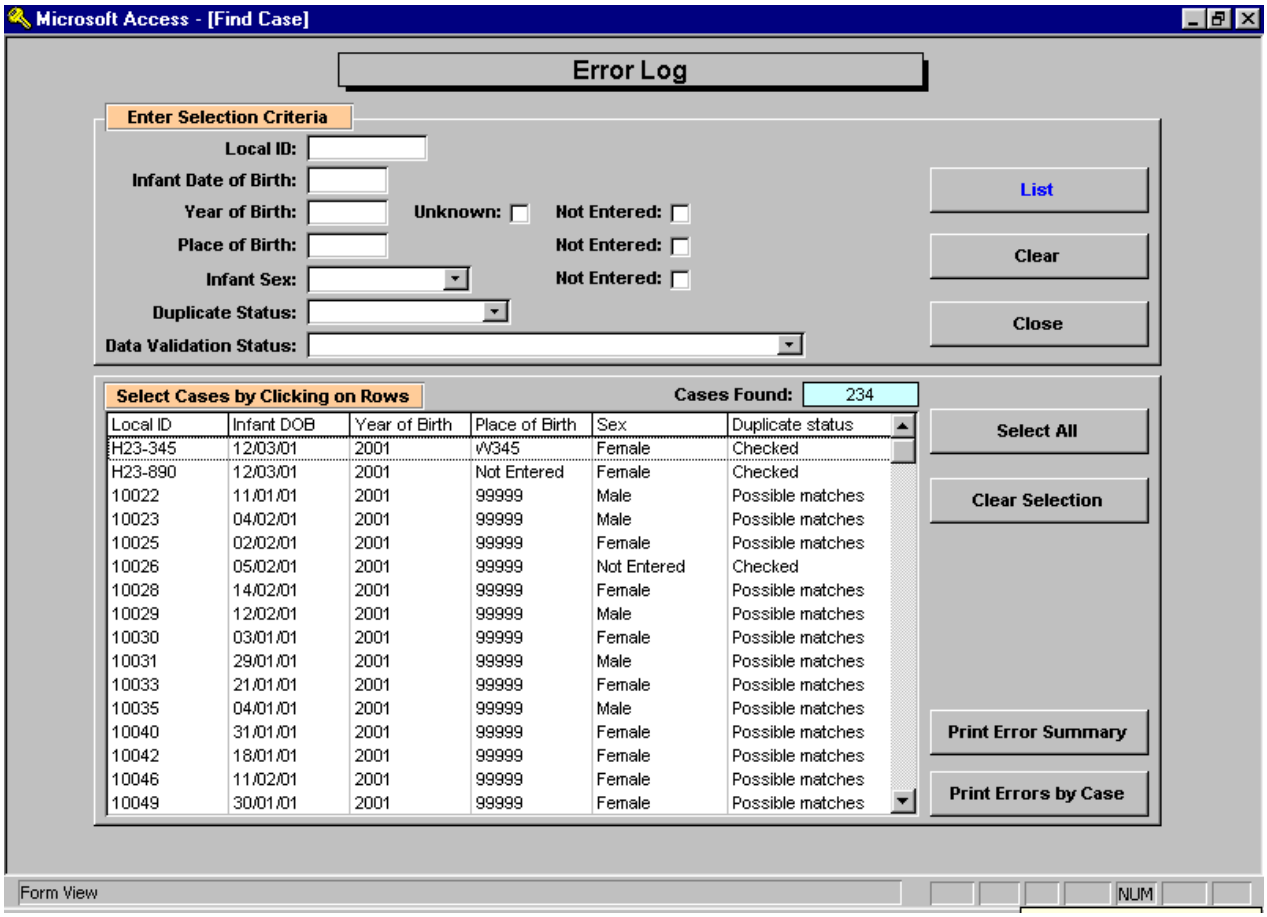


To make a selection enter the criteria as necessary and then click on the ‘Set Criteria’ button. Your current selection will then be displayed in the box on the right of the screen. When you are satisfied that the selection is correct click on the ‘Reports’ button to take you to the report sub menu.

The report menu offers you a number of standard reports you can run on the selected data. In addition, you can alter your selection by clicking on the ‘Selection Criteria’ button and you will be returned to the selection screen. The selection criteria are printed on each report. You can also export selected core, core & non-core and all variables from the reports screen to a .csv file.

5.10 Error Log

The error log facility allows you to list all the Core, Non-Core and Extreme value errors for selected cases. Select the required cases to check using the screen shown below. Once you have selected the cases you can then print the error log either as a summary or as a list case by case using the 'Print Error Summary' and 'Print Errors By Case' buttons.



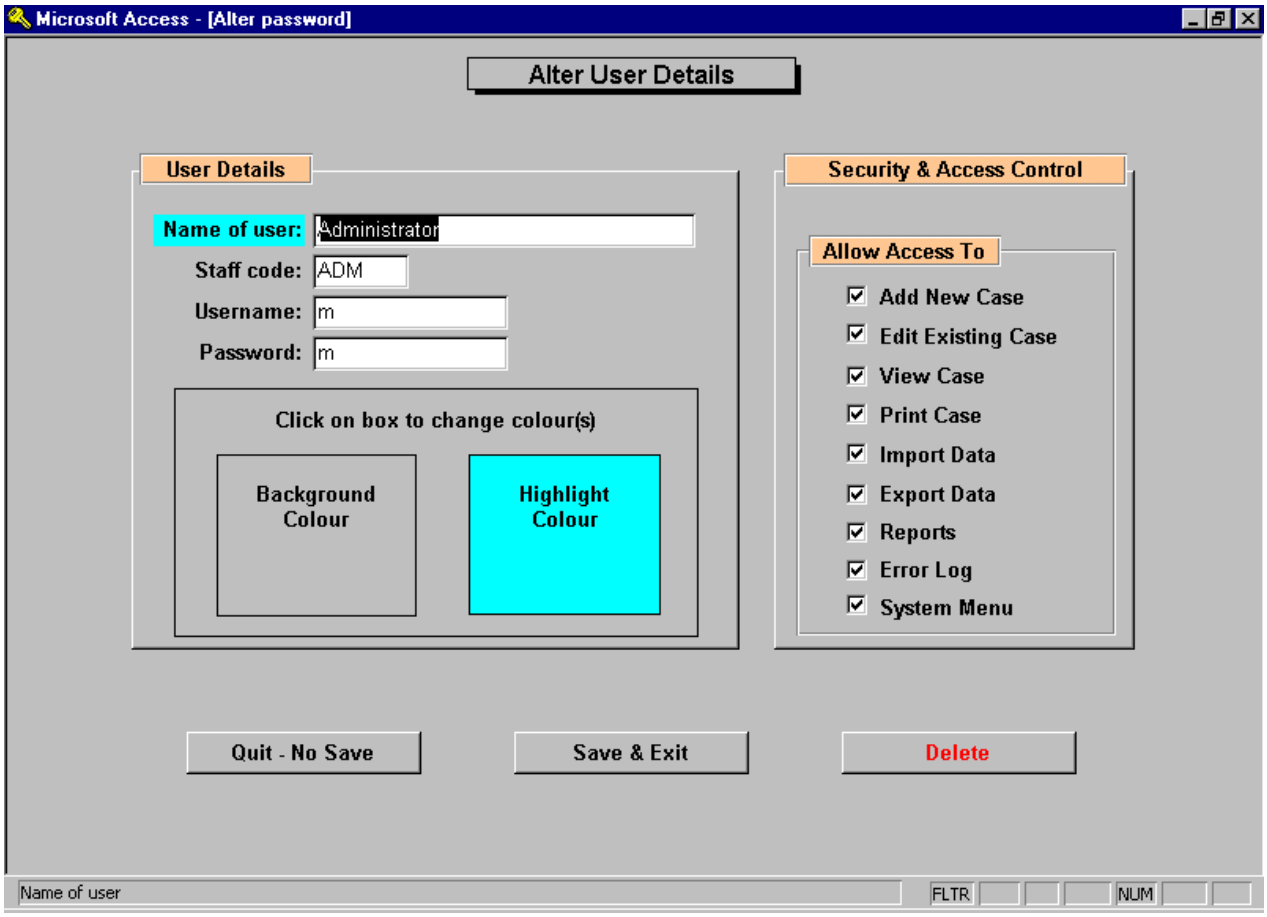
5.11 System menu

The system menu provides you with facilities to alter login details, change the default printer, determine the current location of the data, set your centre name and number, **note** that the centre name will appear on all reports.
You also have the facility to delete a case.

5.11.1 Users & Passwords

Once you have entered the Users & Passwords section you can either set up new user details (click the Add New button) or alter the details of existing users by clicking on the required row in the list box. Please remember to alter the user name and

password for the ‘Administrator’ user, which is distributed with the program. The screen shown below will be displayed.



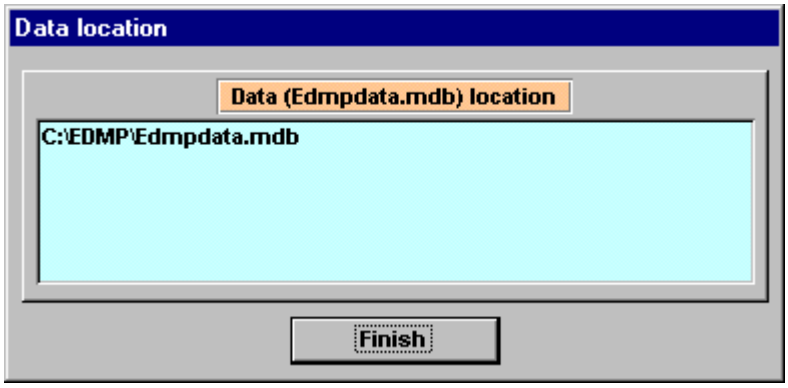
User details allows you to enter (or alter) user details including username and password as well as allow you to alter the personalised screen colour settings for each user. To change screen and highlight colours simply click on the required box on the screen and the standard Windows colour selection screen will appear. ‘Security & Access Control’ allows you to specify which parts of the program are accessible to each user. It is important that at least one user has access to the System Menu!

5.11.2 Set default printer

The default printer facility displays the currently selected default printer and also allows you to select a different default printer by clicking on the ‘Change Printer’ button. All the printers available to your PC will be displayed in the list for you to choose from.

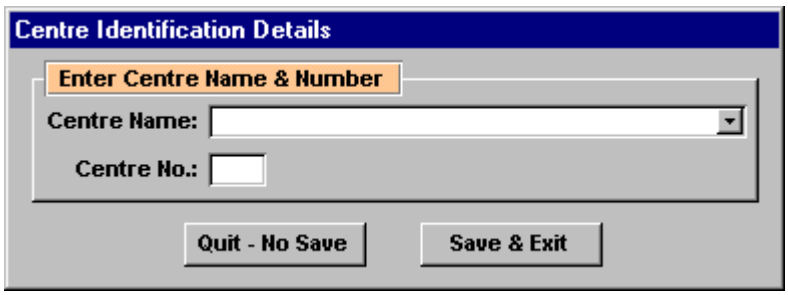
5.11.3 Data location

This facility displays the location of the data file Edmpdata.mdb that the program is currently using.



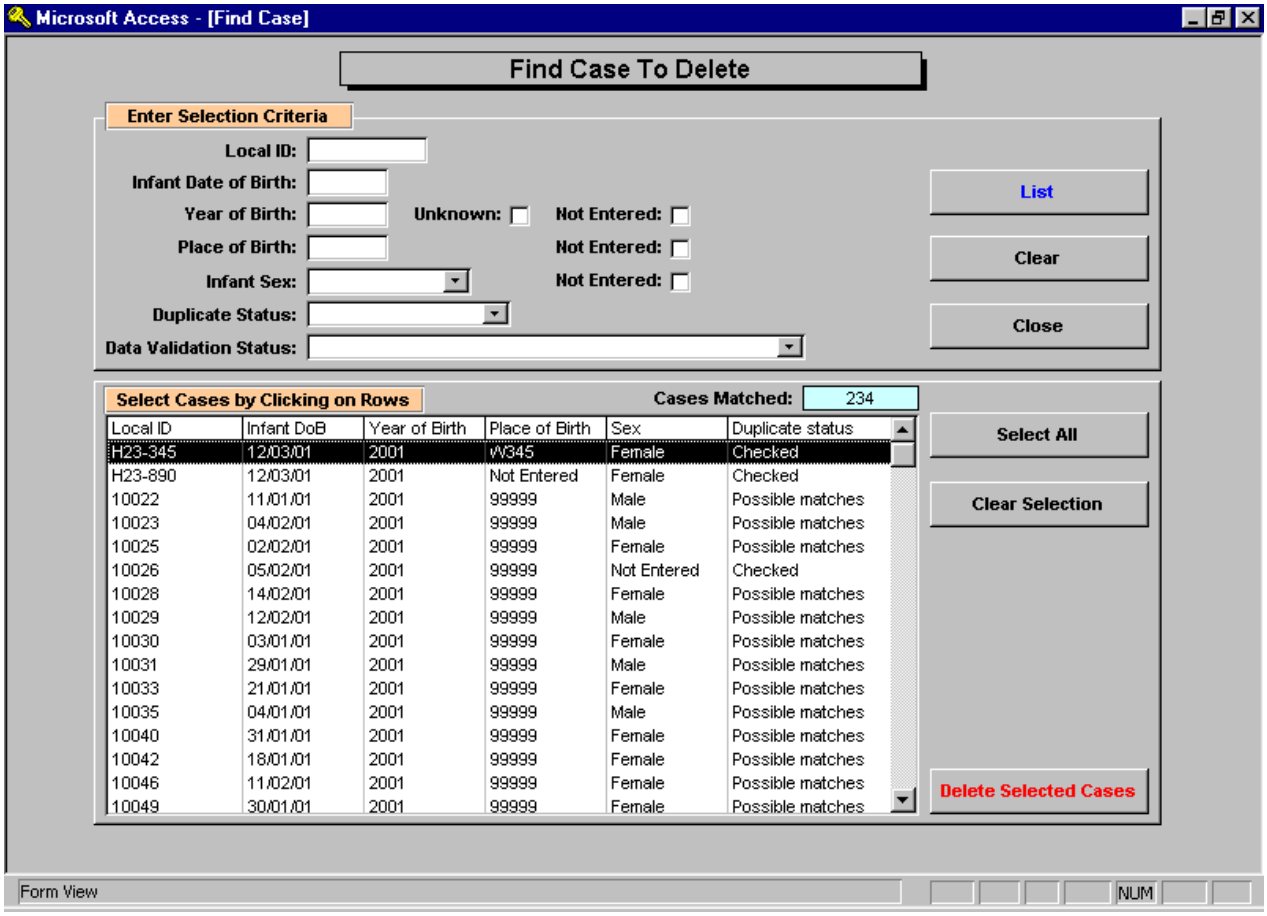
5.11.4 Centre Name & Number

This is where you set your centre name and number. Note that the centre name will appear on all reports. You can select your centre name from the pull down list which will then automatically fill in the centre number, or enter the details yourself.



5.11.5 Delete Case

The delete records option allows you to delete records for selected case(s).
The list box, in the example below, shows case details. These include local ID number, year of birth, place of birth, sex of infant and duplicate status.
Select the case or cases you wish to delete and then click on the ‘Delete Selected Cases’ button. There is also a ‘Select All’ button which highlights / selects all cases.
Please note that there is no ‘undo’ function available to recover deleted cases.



5.12 Routine Maintenance

The file Edmp.mde may grow in size due to frequent use of the Import facility. To counter this you can repair and compact Edmp.mde. This is done by opening Microsoft Access without opening or creating a new database and then selecting ‘Tools’ from the menu bar. Select database utilities and then select the ‘Repair Database’ option. You will then be prompted for the location of Edmp.mde. Repeat the process selecting the ‘Compact Database’ option.

Part 6
Data Validation Routines

Validation of data should be done using the EDMP before data is transmitted to Central Registry. The EDMP includes the following routines:

6.1 Duplication checks

- The local identity number within a registry cannot be duplicated
- Cases with the same values of three or more key variables (date of birth, sex, birthweight +/- 100 g, maternal age) should be checked as possible duplicates.
- It is not sufficient to rely on matching the name of the baby or mother for finding duplicates

6.2 Presence of "core" information

All babies must have local identification number, date of birth, sex, no. of babies delivered, type of birth or abortion, birthweight and/or gestation, and at least one malformation or syndrome code. Before sending data to the Central Registry any cases with this "core" information lacking should be reviewed to find out if it is possible to complete the missing data. For chromosomal anomalies and preferably for all malformations, maternal age should be regarded as "core" information.

6.3 Range Error Checks

- All codes should be within the range of acceptable values as described in Section 3.
- Unusual values should be verified eg.
    1. mother's age outside the range 15 to 50
    2. total previous pregnancies greater than 12
    3. gestational age outside the range 12 to 45
    4. birthweight above 6000g
- The malformation code should start with a letter (ICD10).

6.4 Logical validation

The following checks of the logical relation between variables are suggested. Sometimes these checks only indicate unusual but possible relationships between different items of information (for example a livebirth at 19 weeks gestation). The more unusual the information, the more likely that there is a coding error. Therefore, these cases should be checked to make sure that the information is correctly coded.

- Type of birth, gestational age, and birthweight

    1. Type of birth, length of gestation and birthweight should be compatible according to the definitions used by the local registry (see instructions)

    2. Maximum birthweights for gestational age are usually:

20-22 weeks	750 g
23-25 weeks	1000 g
26-27 weeks	1500 g
28-31 weeks	2000 g
32-35 weeks	3500 g
36-37 weeks	4000 g
38+ weeks	6000 g

        Birthweights above these values should be checked

    3. Birthweights less than 500g should be verified if coded as a live or stillbirth

- Date of discovery, "when discovered" and condition at discovery

    1. Date of discovery of malformation must be before the date of birth if "when discovered" is prenatal (code 6). Date of discovery of malformation must be at or after the date of birth if "when discovered" is at birth (code 1) or postnatal (code 2,3,4,5).

    2. For livebirths, the interval between the date of discovery and the date of birth should be compatible with "when discovered".

    3. If "when discovered" is prenatal (code 6) and "condition at discovery" is dead (code 2), then type of birth should be a spontaneous abortion (code 3) or a stillbirth (code 2).

4. If " when discovered" is "at abortion" (code 7), then the type of birth should usually be a spontaneous abortion (code 3). If "type of birth" is induced abortion (code 4), "when discovered" is usually "prenatal" (code 6).

- Death

  If survival beyond a week of age is coded as no, then date of death should be known and should be within one week of birth.

- Parental age

  If date of birth of mother (father) is known, the age of mother (father) must also be filled in . The age of mother (father) must be the number of completed years between the date of birth of the mother (father) and the date of birth of the baby.

- Previous reproductive history

  1. If the total number of previous pregnancies is coded as zero, the sum of the coded numbers of births and abortions must also be equal to zero.

  2. The total number of previous pregnancies (if coded as known) cannot be greater than the sum of coded numbers of still and live births and spontaneous and induced abortions.

  3. If the total number of previous pregnancies is less than the sum of the coded numbers of births and abortions (if coded as known), be sure that the mother has experienced a multiple birth or multiple abortions previously.

- Previous reproductive history and maternal age

  Implausible combinations of maternal age and number of previous pregnancies are age 15 or less with 2 or more previous pregnancies, or age 16-19 with 3 or more previous pregnancies.

6.5 Frequency checks

Before sending a batch of data to EUROCAT central registry, produce some frequency tables to ensure that the quality of the information corresponds to the aims of the local registry. NB: This check is not automatically perfomed by the EDMP.

- A high frequency of unknown values for any variable should prompt an investigation of how the recording of the variable can be improved, and the registry should communicate with Central Registry concerning how the variable can be used in analyses of data, or if there is selection bias in the distribution of known values.

- It may be useful to check that all malformation codes which have been used only once are valid codes.

- Malformation codes should usually be specified to 5 or 6 digits as appropriate. A high frequency of poorly specified codes should prompt investigation.

- The number of cases where “total previous pregnancies” or “previous livebirths” has been coded “0” should correspond approximately to the number of cases expected from the proportion of primiparous mothers in the population.

- Cross-tabulation of maternal age and number of previous pregnancies should show a distribution roughly corresponding to the distribution in the total birth population.

Part 7
Minor Anomalies for Exclusion

Reports of cases with the following anomalies are *not* to be transmitted to the EUROCAT Central Registry unless occurring in combination with other specified anomalies

	ICD 9	ICD 10
Anomalies of eye:		
Stenosis or stricture of lacrimal duct	74365	Q10.5
Anomalies of ear:		
Minor or unspecified anomaly of ear	7443	Q17.9
Preauricular appendage, tag or lobule	74411	part of Q17.0
Other appendage, tag or lobule	74412	part of Q17.0
Cardiovascular system:		
Functional or unspecified cardiac murmur	7852	P29.81
Absence or hypoplasia of umbilical artery, single unbilical artery	7475	Q27.0
Patent ductus arteriosus in babies <37 weeks or <2500 grams	7470	Q25.0
Digestive system:		
Tongue tie	7500	Q38.1
External genitalis:		
Undescended testicle and unspecified ectopic testis	7525	Q53
Congenital hydrocele or hydrocele of testis	7786	P83.5
Phymosis	605	N47
Hypospadias when the meatus lies before the coronary sulcus, glandular or 1st degree hypospadias (NB:exclusions done by local registry)	75260	Q540
Limbs:		
Clicking hip	75432	R29.4
Clubfoot of postural origin	75473	Q66.8
Postural or unspecified metatarsus varsus or metatarsus adductus	75452	Q66.2
Postural or unspecified talipes calcaneovalgus or pes calcaneovalgus	75460	Q66.4
Minor or unspecified anomalies of toe such as hallux valgus, hallux varus, or "orteil en marteau"	75560	parts of Q72.8
Other musculoskeletal anomalies and anomalies of the integument:		
Spina bifida occulta uncomplicated	75610	Q76.0
Pectus excavatum	75636, 75481	Q67.6, Q76.7
Minor or unspecified anomaly of nose	74819	Q30.9
Minor or unspecified deformity of face	74491	Q18.9
Minor anomaly of nipple	75768	part of Q83.8
Accessory or ectopic nipple	75765	Q83.3
Congenital umbilical hernia	5531	K42
Inguinal hernia	550	K40
Para umbilical hernia	5531	K42
Ventral or incisional hernia	5532	K43
Hiatus hernia	7506	Q40.1
Abnormal palmar crease	7572	Q82.80
Skin tag with surface less than 4 cm^2 : (NB exclusions done by local registry)		
skin tag	75731	Q82.81
Naevus	75738	Q82.5
Angioma	2280	D18.0
Haemangioma	2280	D18.0
glomus tumor	2280	D18.0
Lymphangioma	2281	D18.1
birth mark	75738	Q82.5
Sacral dimple	7578, 6851	-

Part 8
(This section has been updated with the revised Subgroup Definition on 25/10/04)
Definition of EUROCAT Congenital Anomaly Subgroups: ICD9 and ICD10 Codes

EUROCAT Groups Selected for Tabulation in REPORT 8	ICD9-BPA*	ICD10-BPA*	Comments
Nervous System	740, 741, 7420-7425, 7428, 7429	Q00, Q01, Q02, Q03, Q04, Q05, Q06, Q07	
Neural Tube Defects:	7400-7420	Q00, Q01, Q05	
Anencephalus and similar	7400-7402	Q00	
Encephalocele	7420	Q01	Exclude association with anencephalus
Spina Bifida	7410-7419	Q05	Exclude association with anencephalus or encephalocele
Hydrocephaly	7423 [excl 74232]	Q03	Exclude hydranencephaly, exclude association with NTDs
Microcephaly	7421	Q02	Exclude association with NTDs
Arhinencephaly / holoprosencephaly	74226	Q041, Q042	
Eye	7430-7436 [excl 74365], 7438-7439	Q10-Q15 [excl Q105]	
Anophthalmos / microphthalmos	7430, 7431	Q110, Q111, Q112	
Anophthalmos	7430	Q110, Q111	
Microphthalmos	7431	Q112	Exclude association with anophthalmos
Cataract	74332	Q120	
Ear	7440-7442 [excl 74411, 74412]	Q16, Q17 [excl Q179]	
Anotia/microtia	74401, 74421	Q160, Q172	
Anotia	74401	Q160	
Microtia	74421	Q172	Exclude association with anotia
Congenital Heart Disease	7450-7459, 7460-7469, 7470-7474	Q20-Q26	Exclude PDA in preterm/LBW babies (<2,500g or <37 wks) – ICD9 7470; ICD10 Q250
Anomalies of cardiac chambers and connections	74500, 7451, 7453, 7457	Q20	
Common arterial truncus	74500	Q200	
Transposition of great vessels, complete	74510	Q203	
Single ventricle	7453	Q204	
Malformations of cardiac septa	74501, 7452, 7454, 7455, 7456, 7458, 7459	Q21	
VSD	7454	Q210	
ASD	7455	Q211	
AVSD	7456	Q212	
Tetralogy of Fallot	7452	Q213	
Malformations of valves	7460-7467	Q22-Q23	
Tricuspid atresia and stenosis	7461	Q224	
Ebstein's anomaly	7462	Q225	
Aortic valve atresia/stenosis	7463	Q230	
Hypoplastic left heart	7467	Q234	
Malformations of great arteries and veins	7470, 7471, 7472, 7473, 74742, 74743	Q25-Q26	Exclude PDA in preterm/LBW babies (<2,500g or <37 wks) – ICD9 7470; ICD10 Q250
Coarctation of aorta	7471	Q251	

Definition of EUROCAT Congenital Anomaly Subgroups (contd)

EUROCAT Groups Selected for Tabulation in Report 8	ICD9-BPA*	ICD10-BPA*	Comments
Cleft Lip With or Without Cleft Palate	7491, 7492	Q36-Q37	
Cleft Palate	7490	Q35	Exclude association with cleft lip
Digestive System	7503-7505, 7507-7519	Q39, Q400, Q402, Q403, Q408, Q409, Q41, Q42, Q43, Q44, Q45	
Tracheo-oesophageal fistula, oesoph. atr. and sten.	7503	Q390-Q394	
Small Intestinal Atresia	7511	Q41	
Duodenal atresia and stenosis	75110	Q410	
Atresia and stenosis of other parts of small intestine	75111-75112	Q411-Q418	
Ano-rectal atresia and stenosis	75121-75124	Q420, Q421, Q422, Q423	
Internal Urogenital System: Ovaries, Uterus, Renal	7520-7523, 7529, 7530, 7531, 7532, 7533, 7534-7539	Q50, Q510-Q514, Q517-Q519, Q60, Q61, Q62, Q63, Q641-Q649	
Bilateral renal agenesis	75300	Q601, Q604, Q606	
Cystic kidney disease	7531	Q61	
Congenital hydronephrosis	75320	Q620	
Bladder exstrophy	7535	Q641	
External Genital System	7524, 7526, 7527, 7528	Q515, Q516, Q52, Q54, Q55, Q56, Q640	
Hypospadias	75260	Q541-Q543, Q548, Q549	Exclude chordee, glanular hypospadias
Indeterminate sex	7527	Q56	
Limb	7543-7544 [excl 75432], 7545-7547 [excl 75452, 75460,75473], 7550-7551, 7552-7554, 7555-7556 [excl 75560], 7558-7559	Q650-Q656, Q66 [excl Q662, Q664, Q668], Q682-Q685, Q69, Q70, Q71, Q72, Q73, Q74	
Limb reduction	7552-7554	Q71-Q73	
Upper limb reduction	7552	Q71	
Complete absence of upper limb	75520	Q710	
Absence of upper arm and forearm with hand present	75521	Q711	
Absence of both forearm and hand	75523	Q712	
Absence of hand and fingers	75524	Q713	
Longitudinal reduction defect/shortening of arm	75525-75527	Q714-Q718	
Lower limb reduction	7553	Q72	
Complete absence of lower limb	75530	Q720	
Absence of thigh and lower leg with foot present	75531	Q721	
Absence of both lower leg and foot	75533	Q722	
Absence of foot and toe	75534	Q723	
Longitudinal reduction defect/shortening of leg	75535, 75536	Q724-Q728	
Polydactyly	7550	Q69	
Syndactyly	7551	Q70	

Definition of EUROCAT Congenital Anomaly Subgroups (contd)

EUROCAT Groups Selected for Tabulation in Report 8	ICD9-BPA*	ICD10-BPA*	Comments
Musculoskeletal and Connective Tissue	7444-7445, 7448-7449 [excl 74491], 7480-7481 [excl 74819], 7501-7502, 7540-7542, 7548 [excl 75481], 7560-7568 [excl 75610, 75636], 7569, 5240	Q18 [excl Q189], Q30 [excl Q309], Q380, Q382-Q389, Q67 [excl Q676], Q680, Q688, Q75, Q76 [excl Q760, Q767], Q77, Q78, Q79, Q8704, Q8705, Q8708, Q870A, K070	
Choanal atresia	7480	Q300	
Craniosynostosis	75600	Q750	
Pierre Robin Syndrome	75603	Q8708	
Mandibulofacial dystosis (Treacher-Collins, Franceschetti)	75604	Q754, Q870A	
Oculomandibular dysostosis (Hallerman-Streiff)	75605	Q755, Q8705	
Goldenhar's syndrome	75606	Q8704	
Chondrodystrophies, osteodystrophies	7564, 7565	Q77, Q78	
Diaphragmatic hernia	75661	Q790	
Omphalocele	75670	Q792	
Gastroschisis	75671	Q793	
Prune Belly Sequence	75672	Q794	
Chromosomal	7580-7583, 7585-7589 [excl 758620]	Q90-Q94, Q96-Q99	Exclude balanced translocations, and Turner's phenotype, karyotype normal
Down syndrome	7580	Q90	
Patau syndrome/trisomy 13	7581	Q914-Q917	
Edward syndrome/trisomy 18	7582	Q910-Q913	
Other trisomies and partial trisomies of autosomes	7585	Q92	
Monosomies and deletions from the autosomes	7583	Q93	
Turner's syndrome	75860, 75861, 75862, 75869	Q96	
Klinefelter's syndrome	7587	Q980-Q984	

* ICD9/10 with British Paediatric Association extension