EUROCAT GUIDE 1.1

Instructions for the Registration of Congenital Anomalies

EUROCAT GUIDE 5

Classification and Coding of Congenital Anomalies

An E.E.C. Concerted Action Project

EUROCAT Central Registry
Department of Epidemiology
Catholic University of Louvain
Brussels, 1200

1990

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Foreword

This guide-book is intended for use in all the Centres participating in the EUROCAT Project of the European Economic Community for the registration of congenital anomalies. It represents both a synthesis and an up-dating of previous publications : (a) EUROCAT Guide-lines for Registration of Congenital Abnormalities and Multiple Births, 1980, (b) EUROCAT Guide-lines for Tabulation of Congenital Abnormalities and Multiple Births, 1981, (c) EUROCAT Guide-lines for Data Security, 1981, (d) EUROCAT Guide 1 for the Registration of Congenital Anomalies, 1984.

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Contents

I. Objectives of the EUROCAT Programme

EUROCAT is a Concerted Action of the European Economic Community (E.E.C.) for the epidemiologic surveillance of congenital anomalies. The Concerted Action was established by Council decision in February 1978 (OJ No L52, 23.03.1978, p 20) and has continued as part of the successive Medical Research Programmes.

The specific objectives of the EUROCAT programme are :

1. to establish in each country of the E.E.C. one or several regional registers of congenital anomalies providing reliable epidemiologic information on the occurrence of the registered conditions in the progeny of the population living in a defined geographic area;

2. to harmonize the methods of diagnosis and of data collection in order to ensure the comparability of statistics between participating centres;

3. to monitor the occurrence rate of congenital anomalies in the progeny of different population groups in order to identify any unexpected frequency;

4. to investigate the risk associated with possible teratogenic or mutagenic factors;

5. to create in each country an area where reporting is reliable, so that base line rates are available for calibrating any information system established at national level for the detection of adverse environmental influences;

6. to evaluate the effectiveness and efficiency of screening programmes, of preventive measures, and of treatment methods;

7. to provide a well documented set of cases recorded in a defined population for clinical research.

The surveillance of congenital abnormalities began in 1979 with the participation of 12 centres. In 1989, 23 centres from the 12 countries of the E.E.C. were collaborating in the Project (listed in Section V). Three centres from countries outside E.E.C. are also participating in the programme. Other centres within or outside the E.E.C. can join the study.

Each EUROCAT Registry is directed by a Registry Leader (listed in Section V) who is responsible for day to day running of the regional

registry. The financing of the activities in each Registry is the responsibility of the Member States of the E.E.C.

The coordination of the EUROCAT Project is financed by the Commission of the E.E.C. and is carried out by a Project Leader. The coordinating centre (EUROCAT Central Registry) is situated in the Department of Epidemiology, School of Public Health, University of Louvain, Brussels, Belgium The scientific supervision of the Project is the responsibility of the COMAC-Epidemiology of the E.E.C.

II. General Outline of Registration

Registration covers structural malformations, chromosomal abnormalities, metabolic disorders and hereditary diseases. Isolated minor anomalies are excluded (see list of cases for exclusion, Section VI).

The reference population comprises all births to women resident in a geographically defined area. Where it is not possible to achieve this, the reference population may be defined as the total births to women (whether resident or not) taking place in the study area.

There is no limit to age at registration. It is recommended to achieve complete registration of cases in induced abortions for fetal anomaly at any gestational age, in fetal deaths of 20 weeks gestational age or more, and in liveborn children up to one year of age.

Multiple sources of information are to be used for case-identification. They include birth and death certificates, maternity and hospital records, reports of cytogenetic laboratories and of pathology services, reports of maternal and child health services.

For each case, standard information is recorded about the child, the pregnancy and the parents (see Section VIII). Additional data may be collected in each registry according to local interest.

III. Information to be Transmitted to the Central Registry

The names and addresses of cases are kept at the local registry and are not sent to the Central Registry. The local identity number, unique for each baby, is transmitted.

The cases for which the diagnosis of malformation is well established are to be transmitted to the Central Registry regularly. The cases which are certainly malformed but for which the exact diagnosis is not yet certain should also be transmitted. When further information is available about a case already notified, an amending report is to be transmitted. The cases for which a malformation is only suspected are to be recorded locally and transmitted only when the diagnosis is confirmed by follow-up.

Each case-record is transmitted to the Central Registry using a standard paper form (see transmission form, Section VII). Magnetic tapes or diskets may be used for data transmission provided that the information and format are compatible with EUROCAT requirements, and that requests for additional written specifications can be met.

IV. Guide-Lines for Data Security

The fulfilment of the objectives of the EUROCAT project implies, for each participating centre, the recording of the identity of malformed babies and their parents along with a list of social and medical private information. At local level the use of named records is needed (1) to link reports arriving from several sources, and so avoiding multiple registrations; (2) to allow the follow-up of cases which is necessary to ascertain the diagnosis and to study the outcome of malformed children; (3) to trace the cases in order to conduct prospective or retrospective etiological studies; (4) to ensure the delivery of all possible aid to the malformed children and their families.

The keeping of such a register raises at local level the problems of privacy, confidentiality and acceptability to the concerned families and to the population. It is thus essential that local conventions and/or national regulations must be respected by each local registry. The local registry is kept under the responsibility of the Regisry Leader or the Head of the Department concerned.

In order to perform epidemiological surveillance, data collected by each participating centre are centralized. The EUROCAT Central Registry is presently located in the Department of Epidemiology, at the Catholic University of Louvain, in Brussels, Belgium. As this procedure involves the transmission of data over country borders, the strongest precautions are taken against any unauthorized use of the data bank and against any breach of confidentiality.

At the present time, there is no specific data protection act in Belgium and no special recommendations have been issued by the E.E.C. However, the Assembly of the European Science Foundation issued on November 12th, 1980 a statement concerning the protection of privacy and the use of personal data for research which lays down general principles. The EUROCAT Guide-lines are considered to be in agreement with these recommendations.

The adopted procedure is as follows :

1. At local level, personal data, defined as any information relating to an identified or identifiable individual, are guarded at the local registry department under the responsibility of the Regisry Leader or the Head of the Department.

2. Information about each case that is to be transmitted to the EUROCAT Central Registry is stated in Sections III, VII and VIII.

3. No name or detailed address or detailed location of birth are transmitted to the EUROCAT Central Registry. Local codes are used for designating places of birth and places of residence. These codes used in transmitted records should be for sufficiently large groups so that individual cases cannot be identified at the Central Registry.

4. From each local Registry, data are transmittted to the Central Register by using either the EUROCAT transmission form (see transmission form, Section VII), or magnetic tapes containing coded information.

5. Transmission forms or magnetic tapes are sent in batches by mail.

6. At the Central Registry, the transmitted local forms and magnetic tapes are retained in locked cabinets. Access is only available to EUROCAT Registry Staff.

7. The transmitted data are entered into the computer whose magnetic storage units are located within the department. A copy of the computerized file is retained in a locked cabinet.

8. Access to the computer file is restricted to the Registry Staff members. A password is used.

9. No personal and medical information concerning individual cases will be released other than to the registry from which the data was sent. For research use centrally, only statistical data will be available and only through the staff in charge of the Registry.

10. For the EUROCAT file on the central computer, there is no way in which an individual can be identified and the EUROCAT Registry cannot be linked with any other registry.

11. If specific enquiries and researches concerning individual cases and needing additional information are to be conducted, the project will be first submitted to the Project Management Group. Such studies will usually start by identifying cases in the Central Registry. Further information will be obtained by reference to the original local form held at the Central Registry. From thence enquiries will be made which will refer to the local registry and may involve reference to medical notes or to attendant physicians. An approach to individual families will be asked for only if no other means can be used and if the study is considered to be of sufficient importance by the Project Management Group and local ethical committees if such exist.

12. Transmitted data will be retained at the Central Registry for at least 10 years from the date of receipt when a decision will be made on the merits of retaining them for longer.

13. At the EUROCAT Central Registry, the security of data is under the responsibility of the Project Leader and of the Head of the Department of Epidemiology of the Catholic Unversity of Louvain.

V. List of Participating Centres and Registry Leaders

West-Flanders	Belgium	**Prof. R. Beckers** Elf Julistraat 29, B - 8000 Brugge Tel : (50) 33.21.82
Hainaut	Belgium	**Dr F. Lys** Ecole de Santé Publique, U.C.L. - EPID 30.34, Clos Chapelle-aux-Champs 30, B - 1200 Bruxelles Tel : (2) 764.33.46/23
Odense	Denmark	**Dr E. Garne** Institute of Medical Genetics, Odense University, J.B. Winslows Vej 17, DK - 5000 Odense C Tel : (9) 11.33.33 ext. 2092
Paris	France	**Dr J. Goujard** I.N.S.E.R.M., Unité 149, Boulevard Port-Royal 123, F - Paris 75014 Tel : (14) 326.00.46
Strasbourg	France	**Prof. C. Stoll** Institut de Puériculture, Hospice Civil de Strasbourg BP 426, Rue de la Porte de l'Hôpital 23, F - 67091 Strasbourg Cedex Tel : (88) 16.10.12 ext. 3048
Marseille	France	**Dr S. Aymé** Unité 242 Physiopathologie chromosomique, Groupe Hospitalier de la Timone, Hôpital d'Enfants, F - 13385 Marseilles Cedex 5 Tel : (91) 92.14.31

West-Berlin	Germany	**Prof. K. Bergmann** Div. Pub. Health Berlin and Statistics, Federal Health Office(s), General Pape Str. 62, D - 1 Berlin 42
Athens	Greece	**Dr S. Missiou-Tsagaraki** Children's Hospital Agia Sophia, Institute of Child Health, GR - Athens 11527 Tel : (1) 770.43.08
Emilia Romagna	Italy	**Dr E. Calzolari** Istituto di Genetica Medica, Via L. Borsari 46, I - 44100 Ferrara Tel : (532) 35021
Firenze	Italy	**Dr C. Galanti** Regiona Toscana, Dipartimento Sicurezza Sociale, Via di Novoli 26, I - Firenze Cap 50100 Tel : (55) 43.77.985 - 43.93.275
Umbria	Italy	**Dr A. Calabro** Clinica Pediatrica, University di Perugia, Monteluce I - 06100 Perugia Tel : (75) 25.913 - 23.494 - 26.152
Dublin	Ireland	**Dr Z. Johnson** Eastern Health Board, Jame's Street 1, IRL - Dublin 8 Tel : (1) 53.79.51
Galway	Ireland	**Dr D.F. Lillis** Regional Hospital,Dept of Paediatrics, IRL - Galway Tel : (91) 24.222

Luxemburg	Luxemburg	**Dr D. Hansen-Koenig** Ministère de la Santé Publique, Médecine Préventive et Sociale, Rue Goethe 22, L - 1637 Luxembourg Tel : (352) 408.01
Groningen	Netherlands	**Dr L.P. Ten Kate** Department of Human Genetics, University of Groningen, Ant. Deusinglaan 4, NL - 9713 AW Groningen Tel : (50) 63.29.52
Beija	Portugal	**Dr M. De Jesus Feijoo** Servico de Genetica Medica, Hospital de Egas Moniz, R. da Junqueira 126, P - 1300 Lisboa Tel : (11) 64.63.41/64.00.89
Glasgow	United Kingdom	**Dr D.H. Stone** University of Glasgow, Dept of Child Health & Obstetrics, Greater Glasgow Health Board, Lilybank Gardens 1, GB - Glasgow G12 8RZ Tel : (41) 339.31.18 /.9
Liverpool	United Kingdom	**Prof. J.R. Owens** Institute of Child Health, Department of Child Health, Alder Hey Children's Hospital, Eaton Road, GB - Liverpool 112 2AP Tel : (51) 228.48.11
South Glamorgan	United Kingdom	**Prof. K.M. Laurence** Welsh Nat. School of Medicine, University of Wales, Child Health Lab -Department of Child Health, Heath Park, GB - Cardiff CF4 4XN Tel : (222) 761.731

Belfast	United Kingdom	**Prof. N.C. Nevin** The Queen's University of Belfast, Floor A, Tower Block, Belfast City Hospital, Lisburn Road, GB - Belfast BT9 7AB Tel : (232) 32.92.41 ext. 2851/2873

Members not in E.E.C. countries

Malta	Malta	**Dr A. Cuschieri** Dept Biomedical Sciences, The University of Malta, Msida, Malta Tel : (356) 51.66.55
Lausanne	Switzerland	**Prof. T. Pexieder** Institut d'Histologie et d'Embryologie, Rue du Bugnon 9, CH - 1005 Lausanne Tel : (21) 49.29.99
Zagreb	Yugoslavia	**Prof. I. Svel** Institut za Zastitu Majke I Djece, Klaiceva 16, YU - 41000 Zagreb Tel : (41) 440.967
Reunion	Reunion	**Dr Tilmont** Association réunionaise pour le dépistage et la prévention des maladies métaboliques et des handicaps de l'enfant B.P. 904 97478 Saint Denis Cedex

Associate Members

IPISMC*	Italy	**Dr P. Mastroiacovo** Clinica Pediatrica, Universita Cattolica, Largo Gemeli 8, I - 00168 Roma Tel : (6) 330.543.48
North-East Italy	Italy	**Prof. R. Tenconi** Clinica Pediatrica dell'Universita di Padova, Via Giustiniani 3, I - 35128 Padova Tel : (49) 821.35.13
Basque Country	Spain	**Dr S. Garcia-Minaur** Registro de Anomalias Congénitas de la CAV, Unidad Neonatal Hospital de Cruces, E - 48903 Baracaldo (Vizcaya) Tel : (94) 499.30.35

Pending approval of membership

Antwerp	Belgium	**Dr B. Standaert** Provinciaal Instituut van Hygiene Kronenburgstraat 45 B - 2000 Antwerpen Tel : (3) 238.51.29
Rotterdam	Netherlands	**Dr R. Tiessen** G.G.D. Rotterdam Postbus 70032 NL - 3000 LP Rotterdam Tel : (10) 433.96.79

* Indagine Policentra Italiana Sulle Malformazioni Congenite

VI. List of Cases for Exclusion

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

Anomalies of eye

- Stenosis or stricture of lacrimal duct (74365).

Anomalies of ear

- Minor or unspecified anomaly of ear (7443).
- Preauricular appendage, tag or lobule (74411).
- Other appendage, tag or lobule (74412).

Cardiovascular system

- Functionnal or unspecified cardiac murmur (7852).
- Absence or hypoplasia of umbilical artery, single umbilical artery (7475).

Digestive system

- Tongue tie (7500).

External genitalis

- Undescended testicle (7525) and unspecified ectopic testis (75253).
- Congenital hydrocele or hydrocele of testis (7786).
- Phymosis (605).
- Hypospadias when the meatus lies before the coronary sulcus, glandular or 1st degree hypospadias (75260).

Limbs

- Clicking hip (75432).
- Clubfoot of postural origin (75473).
- Postural or unspecified metatarsus varus or metatarsus adductus (75452).
- Postural or unspecified talipes calcaneovalgus or pes calcaneovalgus (75460).
- Minor or unspecified anomalies of toe such as hallux valgus, hallux varus, or "orteil en marteau" (75560).

Other musculoskeletal anomalies and anomalies of the integument

- Spina bifida occulta uncomplicated (75610).
- Pectus excavatum (75636 or 75481).
- Minor or unsepecified anomaly of nose (74819).
- Minor or unsepecified deformity of face (74491).
- Minor anomaly of nipple (75768).
- Accessory or ectopic nipple (75765).
- Congenital umbilical hernia (5531), inguinal hernia (550), para umbilical (5531), ventral or incisional (5532), hiatus hernia (7506).
- Abnormal palmar crease (7572).
- Skin tag with surface less than 4 cm^2 : skin tag (75731), naevus (75738), angioma (2280), haemangioma (2280), glomus tumor (2280), lymphangioma (2281), birthmark (75738).
- Sacral dimple (7578 or 6851).

VII. Transmission Form

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Centre No.

EURO(' REPORT ON CONGENITAL ANOMA ES

INFANT

Local ID No.

Date of Birth

Place of Birth

Sex (1=male, 2=female, 3=indeterminate, 9=nk)

No. of babies delivered

Birth order (in multiple set)

No. malformed (in multiple set)

Type of Birth (1=live 2=still 3=spont. abortion) (4=induced abortion, 9=nk)

Birth weight (grams)

Date of L.M.P. and Certainty

Length of gestation (weeks)

Date of death

Survival beyond a week of age (1=yes, 2=no, 9=nk)

Sources of information

DIAGNOSIS - TIME & TECHNIQUES

Date of discovery

When discovered *

If prenatally diagnosed, gest. age at discovery

Condition at discovery (1=alive, 2=dead, 9=nk)

Prenatal diagnosis (1=done, result positive 2=done, result nk) (3=not done 4=result negative , 8=failed, 9=nk)

Amniocentesis

Ultrasound

Chorionic Villi sampling

Other techniques (specify) ______

Karyotype of infant/fetus (specify) (1=done res. k, 2=done res. nk) (3=not done, 8=failed, 9=nk) ______

Post mortem examination (1=done res. k.) (2=done res. nk, 3=not done, 4=macerated fetus, 9=nk)

MOTHER

Residence code

Date of birth

Age at delivery (years)

Reproductive history

Prev. spontaneous abortion n°

Prev. induced abortion n°

Prev. live birth(s) n°

Prev. stillbirth(s) n°

Total Prev. pregnancies n°

Occupation ______

Social status

Racial type

Assisted conception * ______

Illness before pregnancy* ______

Illness during pregnancy * ______

______

Habitual exposures * ______

(specify) ______

Unusual exposure (specify) ______

Drugs (1st trim) 1. ______

(specify) 2. ______

3. ______

FATHER

Date of birth

Age at delivery (years)

Occupation

Social status

Racial type

Chronic illness

DIAGNOSIS - MALFORMATIONS

Syndrome

Malformations present

1. ______
2. ______
3. ______
4. ______
5. ______
6. ______
7. ______
8. ______

McKusick Code/Type of Mendelian inheritance

Mode of transmission (for single gene or chromosomal disorders, 1=familial 2=de novo 9=nk)

Consanguinity *

Prev. sibs notified to EUROCAT (1=yes, 2=no, 9=nk)

Local code No. 1.

2.

3.

Family history of anomaly

Sibs with anomaly * (specify) ______

Mother's family : * (specify) ______

Father's family : * (specify) ______

Confirmation of diagnosis

* : see instructions *italics : for local use only*

Enter additional malformations/comments below :

Name ______

Address ______

______ Post Code ______

(for local use only)

VIII. Instructions for Coding

General comments

There are two types of variable, those for transmission to Brussels and those for local use (in italics).

Coding of variables to be transmitted to Brussels should follow the coding instructions given here.

Local centres can choose their coding system for variables for local use, but suggestions for coding are given in the instructions.

It is suggested that registries record as much detail as possible, to be kept in local files, which may be asked for in future for special studies co-ordinated in Brussels or elsewhere.

When asked to "specify", a space is left for written information in order that further details can be given.

Item	Digits	Code	Instructions	Boxes No
Centre No.	2	01 : W.Vlaanderen (B) 02 : Hainaut (B) 03 : Odense (DK) 05 : Paris (F) 07 : W.Berlin (D) 08 : Firenze (I) 09 : Umbria (I) 10 : Dublin (IRL) 11 : Galway (IRL) 12 : Luxembourg (L) 13 : Groningen (NL) 14 : Glasgow (U.K.) 15 : Liverpool (U.K.) 16 : Belfast (U.K.) 18 : Emilia Romagna (I) 19 : Strasbourg (F) 20 : Zurich (CH) 21 : Zagreb (YU) 22 : Marseille (F) 23 : Malta (M) 24 : I.P.I.S.M.C. (I) 25 : North East Italy (I) 26 : South Glamorgan(U.K.) 27 : Athens (GR) 28 : Beja (P) 29 : Antwerpen (B) 30 : Bilbao (E)	Enter the code allocated to you by the Central Registry	01 - 02

Item	Digits	Cc	Instructions	Boxes No
Data about the infant				
Local Identification number	11	Local code	Each case should have a unique identification number. This number is a maximum of 11 characters long, consisting of either numbers, letters or both. It is preferred that local I.D. numbers do not repeat themselves in different years.	03 - 13

Item	Digits	Code	Instructions	Boxes No
Date of birth			The date of birth/abortion should be known for all registered cases. Day/Month/Year e.g. 31st January 1990 code 310190	14 - 19
Day of birth	2	99 = Not known	If initially the day or month is unknown, the case should be followed up and the information updated as soon as possible	14 - 15
Month of birth	2	99 = Not known		16 - 17
Year of birth	2			18 - 19
Place of birth	5	99999 = Not known	Use local code to identify institutions or other places of birth such as home delivery. Each institution should have a separate code.	20 - 24

Item	Digits	Codes	Instructions	Boxes No
Sex	1	1=Male 2=Female 3=Indeterminate 9=Not known	Indicate chromosomal sex, if known, in case of ambiguous genitalia. 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".	25

Item	Digits	Codes	Instructions	Boxes No
Number of babies/ fetuses delivered	1	1=Singleton 2=Twins 3=Triplets etc, ... 9=Not known	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" (boxes 150 - 156). Give full description of type of conjoined twinning and any other malformations in space for comments and in boxes 157 - 212.	26
Birth order in multiple set	1	1=1st baby delivered 2=2nd baby delivered 3=3rd baby delivered etc, ... 9=Not known	To be completed for multiple delivery only. If singleton delivery, leave blank.	27
N° of malformed in multiple set	1	1=one 2=Two 3=Three, etc, ... 9=Not known	To be completed for multiple delivery only. If singleton delivery, leave blank. Complete one form for each malformed baby in a multiple set.	28

Item	Digits	Codes	Instructions	Boxes No
Type of birth	1	1=Live birth 2=Stillbirth 3=Spontaneous abortion 4=Induced abortion 9=Not known	Type of birth should always be known. The distinction between live birth, 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 abortions 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 done for other reasons than malformation, this should be clearly indicated on the form, or a list of such cases should be sent to Brussels. Usually, early induced abortions where there was no suspicion of malformation before abortion would 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 (boxes 30 - 33) and gestational age (boxes 41 - 42) are recorded.	29

Item	Digits	Code	Instructions	Boxes No
Birth weight	4	9999 = Not known	Complete the weight in grams If less than 1,000 gm : e.g. 540 gm code 0540	30 - 33

Item	Digits	Codes	Instructions	Boxes No
Date of last menstrual period	*6*	*local code*	*For local use* *Proposed instructions :* *Day/Month/Year* *e.g. 31st January 1990 code 310190* *Not known code 999999* *No LMP code 000000*	*34 - 39*
Certainty of L.M.P.	*1*	*local code*	*For local use* *Proposed instructions :* *1=Certain* *2=Uncertain* *3=No LMP* *9=Not known*	*40*

Item	Digits	Code	Instructions	Boxes No
Length of gestation	2	99 = Not known	In completed weeks, after first day of last menstrual period (LMP). If L.M.P. available and certain, calculate gestational age from date of L.M.P. to date of delivery If L.M.P. is available but uncertain, give the corrected gestational age by clinical ascertainment or other means If L.M.P. is not available, give the estimated gestational age by clinical ascertainment or other means	41 - 42

Item	Digits	Code	Instructions	Boxes No
Date of death	6	999999=Not known whether alive or dead	Day/Month/Year e.g. died on 31st January 1990 code 310190 Give Day, Month, and Year as best known. e.g. 990590 means died in May 90 999990 means died in 1990 Code '555555' if known to be dead, but date of death entirely unknown. Code '000000' if known to be alive.	43 - 48
Survival beyond one week of age	1	1=Yes 2=No 9=Not known	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.	49

Item	Digits	Codes	Instructions	Boxes No
Sources of information	*5*	*Local code*	*For local use* *Proposed instructions :* *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*	*50 - 54*

Item	Digits	Code	Instructions	Boxes No
Diagnosis - Time & Techniques				
Date of discovery	6	999999 = Not stated	The date on which the baby was first suspected or recognized as being malformed, even if the detailed diagnosis is not available. Day/Month/Year e.g. 14th August 1990 code 140890	55 - 60
When discovered	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	When the baby was first suspected to be malformed.	61
If prenatally diagnosed gestational age at discovery	2	99 = Not known	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 boxes 55 - 60.	62 - 63
Condition at discovery	1	1=Alive 2=Dead 9=Not known	Condition when malformation first suspected.	64

Item	Digits	Codes	Instructions	Boxes No
Prenatal diagnosis				
Amniocentesis	1	1=Performed, result positive 2=Performed, result NK 3=Not performed 4=Performed, result negative 8=Failed 9=Not known	"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.	65
Ultrasound	1		Same codes and instructions as for box 65.	66
Chorionic Villi Sampling	1		Same codes and instructions as for box 65.	67
Other techniques	1		Same codes and instructions as for box 65. If performed, specify technique.	68

Item	Digits	Codes	Instructions	Boxes No
Karyotype of infant/fetus	1	1=Performed, result known 2=Performed, result NK 3=Not performed 8=Failed 9=Not known	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.	69

Item	Digits	Code	Instructions	Boxes No
Post mortem examination	1	1=Performed, result known 2=Performed, result NK 3=Not performed 4=Macerated fetus 9=Not known	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.	70

Item	Digits	Code	Instructions	Boxes No
Data about the mother				
Residence code	7	9999999 = Not known	Use local code for locality (area) of residence at time of delivery	71 - 77

Item	Digits	Code	Instructions	Boxes No
Date of birth (mother)	6	999999 = If not known or not available	Day/Month/Year e.g. 23rd February 1963 code 230263 Give as much of data as is available e.g. February 1963 code 990263 1963 code 999963	78 - 83
Age at delivery (mother)	2	99 = If not known	In completed years at the time of delivery. If only the year of birth is available, assume that the mother was born on June 30th.	84 - 85

Item	Digits	Codes	Instructions	Boxes No
Reproductive history			In case of a previous multiple pregnancy, count each baby/fetus separately in boxes 86 - 90, but count as one pregnancy in boxes 91 - 92.	
Number of previous spontaneous abortions	1	0=None 1=One 2=Two 3=Three, etc 9=Not known	If a twin pregnancy aborted count as 2	86
Number of previous induced abortions	1	0=None 1=One 2=Two 3=Three, etc 9=Not known	If a twin pregnancy aborted count as 2, unless selective induced abortion was performed	87
Number of previous live births	2	00=None 01=One 02=Two 03=Three, etc... 99=Not known	A twin delivery counts as 2 <u>if both live born</u>, triplets as 3, etc ...	88 - 89
Number of previous stillbirths	1	0=None 1=One 2=Two 3=Three, etc 9=Not known	A twin delivery counts as 2 <u>if both stillborn</u>, triplets as 3, etc ...	90
Total number of previous pregnancies	2	00=None 01=One 02=Two 03=Three, etc 99=Not known	This is total previous <u>pregnancies</u>, not births. The present notified pregnancy is <u>not</u> to be included. Include all previous abortions whether spontaneous or induced. Twin or other previous multiple pregnancies count as 1 in the total. e.g. : 3 previous L.B. + 1 termination of a twin pregnancy = code 04	91 - 92

Item	Digits	Code	Instructions	Boxes No
Occupation (mother)	5	99999 = Not known	Code according to the International Classification of Occupation (ILO). Code with EUROCAT supplement : 99099 Worker 99199 Labourer 99299 Skilled worker 99399 Student 99499 Housewife 99599 Unemployed 99699 Army 99799 Civil servant Use 5-digit code where possible. Use 3-digit code in first 3 boxes, if no further specification is possible, filling the remaining boxes with 99. Code main occupation at the time of conception. Give job, industry, status in written description, if possible.	93 - 97
Social status *(mother)*	*1*		*For local use*	*98*
Racial type or ethnic origin *(mother)*	*1*		*For local use*	*99*

Item	Digits	Code	Instructions	Boxes No
Assisted Conception	1	0=No 1=Induced Ovulation only 2=Artificial Insemination 3=IVF 4=GIFT 8=Other 9=Not Known	If "other", specify the technique. IVF = In vitro Fertilization GIFT = Gamete Intra Fallopian Transfer	100

Item	Digits	Code	Instructions	Boxes No
Illness before pregnancy	4	ICD 0000 = No 0001 = Yes, but no information available 9999 = Not known	Record any illness whether chronic or acute with onset before pregnancy and that may adversely affect fetal development (e.g. : childhood cancer, metabolic disease,...) Give details (age at onset, evolution, etc...) in the space for comments. Use 4 digits of ICD code 9th revision. Abridged list : Hyperthyroidism NOS : 2429 Hypothyroidsm NOS : 2449 Diabetes mellitus NOS : 2509 Obesity : 2780 Epilepsy NOS : 3459 Asthma NOS : 4939	101 - 104

Item	Digits	Code	Instructions	Boxes No
Illness during pregnancy	4	ICD 0000 = No 0001 = Yes, but no information available 9999 = Not known	Record any illness whether chronic or acute with onset during pregnancy. Asymptomatic maternal infection should be recorded. Give details (gestational age at onset, evolution, etc...) in the space for comments. Use 4 digits of ICD code 9th revision (mainly in chapter XI : Complications of pregnancy). Abridged list : Eclampsia NOS : 6426 Hypertension complicating pregancy : 6429 Diabetes mellitus during pregnancy : 6480 Abnormal glucose tolerance : 6488 Anaemia : 6482 Bacteriuria : 6465 For maternal infections, use 4 digits of ICD code as stated in Chapter I. For infections or parasitic diseases do not use the code 760.2 which is unspecific. (The codes in section 771 are reserved to fetal infections). Coxackie : 0749 Cytomegalic inclusion disease : 0785 Herpes simplex NOS : 0549 HIV (AIDS) : 0798 Influenza : 4871 Listeria : 0270 Mumps : 0729 Rubella NOS : 0569 Syphilis : 6470 Toxoplasmosis : 130- Varicella (chicken pox) : 052- Viral hepatites NOS : 0709	105 - 108
Illness during pregnancy	4		Same instructions as above.	109 - 112

Item	Digits	Code	Instructions	Boxes No
Habitual exposures	4	ICD 0000 = No 0001 = Yes, but no information available 9999 = Not known	Record any habitual exposures that may adversely affect the pregnancy (e.g. : smoking, drinking alcohol, drug use, etc..). Use 4 digits of ICD code 9th Revision (mainly in Chapter V : Mental disorders).	113 - 116
Habitual exposures	4	ICD 0000 = No 0001 = Yes, but no information available 9999 = Not known	Same instructions as above.	117 - 120
Unusual exposure	4	ICD 0000 = No 0001 = Yes, but no information available 9999 = Not known	Record any unsusual exposure whether chronic or acute that may adversely affect the pregnancy (e.g. : car accident, carbon monoxide, intoxication, poisoning, etc ...). Use 4 digits of ICD code 9th Revision (mainly in Chapter XVII : Injury and poisoning).	121 - 124

Item	Digits	Code	Instructions	Boxes No
Drugs	2	See instructions next page	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 (i.e. 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 (e.g. : Vitamins A megadoses). Record the proprietary name (trademark) preferably. Details on the dosage and timing are to be recorded 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, Mac Millan 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' boxes 121 - 124.	125 - 126

Item	Digits	Cod	Instructions	Boxes No
			Codes for drugs :	
			00 : No drugs 01 : Atropinics and antispasmodics 02 : Anesthetics, local and general 03 : Hypnotics, sedatives and psychotropics 04 : Antiepileptics 05 : Analgesies, antipyretics and antiinflammatory agents; including opioids 06 : Histamine antagonists, H1 and H2 07 : Antiasthmatic agents, including methylxanthines 08 : Antiarythmics and antithypertensive agents; including cardiac glycosides, adrenergic antagonists, calcium channel blokers 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 : Unknown	
Drugs	2		Same instructions as above.	127 - 128
Drugs	2		Same instructions as above.	129 - 130

Item	Digits	Codes	Instructions	Boxes No
Data about the father				
Date of birth	6	999999 = Not known	Day/Month/Year e.g. 23rd February 1963 code 230263 Give as much of data as is available. e.g. February 1963 code 990263 1963 code 999963	131 - 136
Age at delivery	2	99 = Not known	In completed years at the time of delivery.	137 - 138
Occupation	5	99999 = Not known 88999 = if single mother, father's occupation UK	See "Occupation" under Mother, (boxes 93 - 97).	139 - 143
Social status	*1*		*For local use.*	*144*
Racial type	*1*		*For local use.*	*145*
Chronic illness	*4*		*For local use.* *Proposed instructions :* *See "Illness before pregnancy" under Mother, (boxes 101 - 104).*	*146 - 149*

Item	Digits	Codes	Instructions	Boxes No
Diagnosis - Malformations				
Syndrome	4.2.1		Use ICD 9th revision in the first four digits, the British Paediatric Association Classification of Diseases (B.P.A) in the fifth digit, EUROCAT supplement for sixth digit. Complete six digit code can be found in EUROCAT Guide V. The seventh digit is for central registry. Start the code in the most left hand box. Write names of syndromes, associations and diseases in full. If not a recognizable syndrome, eponym or disease name, leave blank. If a recognizable syndrome, eponym or disease name, with no specific code, then code 8888.88 and specify name in writing. All the anomalies observed by the local clinician should be coded in the remaining boxes for malformations. When two syndromes are present in the same subject, code the more important one in the boxes for syndrome (150 - 156) and the other (157 - 163) one in the boxes for the first malformation. Make sure karyotype information is filled in (box 69), and that autopsy and medical genetics reports have been reviewed, where appropriate. In case of conjoined twins, give full description in the comments section of the form.	150 - 156

Item	Digits	Codes	Instructions	Boxes No
Malformation(s) present :				
Malformation 1	4.2.1		Codes are given in Section XIV 'Congenital Anomalies' of the B.P.A. Specify as fully as possible, up to 6 digits.	157 - 163
Malformation 2	4.2.1		The 7th digit is for official use.	164 - 170
Malformation 3	4.2.1		Start the code in the first box on the left e.g. 7400.2 = Anencephaly	171 - 177
Malformation 4	4.2.1		If no fifth digit exists in the ICD/BPA code or no further specification is known, the fifth digit should be 9 or left blank.	178 - 184
Malformation 5	4.2.1		e.g. 7470.-- = Patent ductus arterious 7560.0- = Craniosynostosis 7560.9- = Unspecified anomalies of skull and face bones	185 - 191
Malformation 6	4.2.1		Similarly, an unknown sixth digit should be coded 9, not 0. A list of minor anomalies for exclusion is given in Section VI of EUROCAT Guide 1.1.	192 - 198
Malformation 7	4.2.1		Only a baby/fetus with minor anomalies and no major anomaly should be excluded.	199 - 205
Malformation 8	4.2.1		When a major anomaly is present, code both the major and the minor anomalies.	206 - 212
			Up to 8 malformations can be coded. If more malformations are present, specify these in the space for comments, including in the eight coded malformations the most important ones, or those included in the list of selected anomalies in EUROCAT Guide V.	
			Give in writing or drawing the fullest description of the malformations available.	

Item	Digits	Codes	Instructions	Boxes No
McKusick Code / Type of Mendelian inheritance	5		This code is to be used for conditions with single gene origin only. The 1st digit designates the mode of inheritance of the condition : 1=Autosomal dominant 2=Autosomal recessive 3=X-linked The full 5-digit code is to be found in McKusick "Mendelian Inheritance in Man". A short list of codes can be found in the EUROCAT list of syndromes in Guide V. The 1st digit may be filled in without the rest of the code, if the full McKusick code is unknown.	213 - 217
Mode of Transmission	1	1=Familial 2=De novo 9=Not known	For conditions with 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.	218

Item	Digits	Codes	Instructions	Boxes No
Consanguinity	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	1st degree = sib, parent. 2nd degree = uncle, aunt, grandparent. 1st cousin once removed = the child of a 1st cousin. If other relation, specify.	219

Item	Digits	Codes	Instructions	Boxes No
Previous sibs notified to EUROCAT	1	1=Yes 2=No 9=Not known	If yes, give the Local code No. in boxes 221 - 253. Include malformed cotwins or sibs from the same pregnancy, irrespective of birth order within multiple set. Exclude conjoined twin.	220
Local code N° of previous sib notified to EUROCAT	11	I.D. no	Enter the local identification number notified to the Central Registry - for family linkage purposes. 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.	221 - 231
Local code N° of previous sib notified to EUROCAT	11	I.D. no	Same instructions as above.	232 - 242
Local code N° of previous sib notified to EUROCAT	11	I.D. no	Same instructions as above.	243 - 253

Item	Digits	Codes	Instructions	Boxes No
Family history of anomaly :			For conditions of monogenic or chromosomal origin, make sure that what is known of the family history of the condition is coded. In this case, do not code family history of unrelated anomalies. For other conditions, code whether the same or another congenital anomaly is present in the family, and specify as fully as possible the type of anomaly. Restrict the family to first and second and third degree relatives (mother, father, sibs, grandparents, aunts, uncles, half-sibs, first cousins). In any case give detailed description of the malformation in the space for comments.	
Sibs with anomaly	1	1=Same 2=Other 3=Same and other 4=No 0,9=Not known	Specify type of anomaly and describe the malformation for each sib. If one sib has both the same anomaly and another anomaly, code only 'same'. If one sib has the same anomaly, and a different sib has another anomaly, code 'same and other'.	254

Item	Digits	Codes	Instructions	Boxes No
Mother's family	1	1=Same 2=Other 3=Same and other 4=No 0,9=Not known	Include mother herself as well as mother's family. Specify type of anomaly and relationship to infant. If the etiology is known (monogenic, chromosomal or environmental disorders), 'same' means the same etiology, even if the spectrum of malformations present is slightly different. If the etiology is unknown or multifactorial, 'same' is a matter of judgement by a qualified coder, but full specification of the anomaly should always be given, whether other or same. 'Same and other' (3) refers to two different relatives. If one relative has both the same and another anomaly code 'same' (1).	255
Father's family	1	1=Same 2=Other 3=Same and othe 4=No 0,9=Not known	Include father himself as well as father's family. Same instructions as above	256

Item	Digits	Code.	Instructions	Boxes No
Confirmation of diagnosis	*1*		*For local use.* *Proposed instructions :* *1=Confirmed* *2=Follow-up needed for confirmation* *3=Not confirmed, but infant lost to follow-up* *9=Not known*	*257*

IX. Scheme for the Preliminary Validation of Data

Validation of data should be done locally when already computerized data are transmitted to the Central Registry.

1. Duplication checks

a) The local identity number within a registry cannot be duplicated.

b) 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. The number of variables used in the check depends on the size of the registry.

c) It is not sufficient to rely on matching the name of the baby or mother for finding duplicates.

2. Presence of "core" information

All cases 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 information. For chromosomal syndromes, and preferably for all malformations, maternal age should be regarded as "core" information.

3. Range error checks

a) All codes should be within the range of acceptable values as described in Section VIII.

b) Unusual values should be verified, e.g. :
mother's age outside the range 15 to 50,
total previous pregnancies greater than 12,
gestational age outside the range 12 to 45,
birthweight above 6000 g.

c) The malformation code should start in the first of the six places given for the code. The range of usual values for the first 4 digits of the malformation code is
0900, 2100-2399, 2439-2869, 3350-3351, 3590, 369-, 389-, 4253-4254, 5240-5241, 5530, 5532, 7400-7599, 7607, 7623, 7628, 7710-7712.

Other codes should be checked to verify whether the code is correct, or whether the condition coded is a congenital anomaly.

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). Since the more unusual the information, the more likely that there is a coding error, these cases should be checked to make sure that the information is correctly coded.

a) Type of birth, gestational age and birthweight

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

(ii) 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.

(iii) Birthweights less than 500 g should be verified if coded as live or stillbirth.

b) Date of discovery, "when discovered" and condition at discovery

(i) Date of discovery of malformation must be before the date of birth if "when discovered" is prenatal (code 6). Date of discovery 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).

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

(iii) 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).

(iv) 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).

c) Prenatal diagnosis

If "when discovered" is prenatal, one of the prenatal diagnostic techniques should be coded as having been performed with positive result. If the result of all prenatal diagnostic techniques is negative or unknown, then "when discovered" cannot be prenatal.

d) 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.

e) 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.

f) Previous reproductive history

(i) 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.

(ii) 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.

(iii) 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.

g) Previous reproductive history and maternal age

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

h) Malformations

(i) If there is a single malformation, it should not be in the list of exclusions (Section VI).

(ii) Blank codes should only come after all malformations have been coded - they should not be inserted between two malformations.

(iii) If a chromosomal condition is coded, karyotype of infant, fetus should be verified. If karyotype is coded as unknown, the fifth digit of the chromosomal syndrome code must be "9". If a chromosomal anomaly is coded where the fifth digit is not 9, then karyotype should be coded "done, result known".

(iv) If a fetal infection is coded, maternal illness during pregnancy should also be coded.

i) Family history

(i) If mode of transmission is coded familial, and type of Mendelian inheritance is not recessive then family history of anomaly in sibs, mother's family or father's family should be known and coded.

(ii) If type of Mendelian inheritance is autosomal recessive, then mode of transmission, should not usually be "de novo".

5. Frequency checks

Before sending a batch of data to Brussels, produce some frequency tables to ensure that the quality of the information corresponds to the aims of the local registry.

a) 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.

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

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

d) The number of cases where "total previous pregnancies" or "previous livebirths" has been coded "0" should correspond approximately the number of cases expected from the proportion of primiparous mothers in the population.

e) Crosstabulation of maternal age and number of previous pregnancies should show a distribution roughly corresponding to the distribution in the total birth population

EUROCAT GUIDE 5

Classification and Coding of Congenital Anomalies

An E.E.C. Concerted Action Project

EUROCAT Central Registry
Department of Epidemiology
Catholic University of Louvain
Brussels, 1990

In order to increase flexibility, and to allow codes to be added to and changed to keep up with developments in the field of congenital anomalies, EUROCAT Guide 1.1 and Guide 5 are being issued as a folder with looseleaf pages. Each time changes are made, the updated version of the appopriate pages will be sent to you for insertion in the folder.