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Appendix 2
Data Quality Indicators

Introduction
Complex factors influence the quality of data collected by a congenital anomaly registry. How, where and when are diagnoses of congenital anomaly made to residents of the region? How does the registry obtain and verify this information and how does it code it? Registry data are never a "perfect" description of which babies have congenital anomalies in the population and precisely what those anomalies are. Moreover, diagnostic definitions and methods change over time.

Registries may need to make difficult decisions about which types of information to prioritize in order to allocate limited resources, particularly whether to devote resources to collection of exposure information as well as diagnostic information. Some types of information are easier to obtain in some regions than others, depending on specialist referral systems for affected children, confidentiality restrictions, what is recorded in medical notes, availability of computer databases, and willingness to collaborate of key professionals.

EUROCAT's policy is to strive for high quality, accompanied by transparency as to strengths and weaknesses in data quality. Making Registry Descriptions and Data Quality Indicators (DQI) freely available will allow registries to evaluate their performance in relation to other registries, and will allow appropriate interpretations to be made of the results of data analyses. The DQI only have relevance in relation to the objectives of EUROCAT. Different data strengths are needed to participate in timely statistical monitoring in relation to environmental teratogenic exposures, or to evaluate the population sensitivity of prenatal screening for detecting affected
pregnancies, or to establish the prevalence of rare genetic syndromes.

The first part of the evaluation of data quality is to read the detailed registry description (available on the EUROCAT website). Key questions to address in evaluating these registry descriptions include the following:

1) Does the registry describe its methods in enough detail? If not, the data emanating from the registry must be regarded as uninterpretable.
2) Is the registry fully population-based? If it covers residents of an area, how does it ensure coverage of residents delivering or seeking paediatric services elsewhere? If it is not entirely population-based, how does it avoid inclusion of selective referrals of high risk pregnancies into registry hospitals?
3) How does the registry ensure coverage of liveborn cases diagnosed after the early neonatal period?
4) How does the registry ensure coverage of late fetal deaths and stillbirths?
5) By what process are terminations of pregnancy following prenatal diagnosis identified in the population?
6) What specialist services are accessed for information, and are these services used for case identification or only for follow-up of known cases?

The second part of the evaluation of data quality is to look at the data generated by the registers.

The following sections provide a set of Data Quality Indicators and a description of completeness of registry data transmitted to the EUROCAT Central Database. The DQI of a particular registry can be compared to the EUROCAT average. Strong deviations on either

side of the average should be examined. The set of data quality indicators has been produced under the headings:

Completeness of case ascertainment
Accuracy of Diagnosis
Completeness of Information on core and non-core EUROCAT variables
Timeliness of data transmission
Availability of Denominator Information

This first ever set of DQI was discussed in Poznan June 2005.

List of Data Quality Indicators (1999-2003)

Ascertainment

- Total congenital malformations prevalence = All cases in malformation chapter ICD10 (Q chapter) or ICD9 (range 740-759), including outside malformation codes (D821, D1810, P350, P351, P371, D215, 27910, 2281, 7710, 7711, 77121). EUROCAT minor anomalies are excluded.

- Ratio of Spina bifida to Anencephalus.

- Prevalence NTD = Neural Tube Defects

- Prevalence selected cardiac malformations.
  Hypoplastic left heart, Transposition of Great Vessels, Tetralogy of Fallot, Coarctation of aorta or Common arterial truncus.

- Prevalence selected postnatal diagnosed malformations
  Corpus callosum anomalies, Cataract, Coarctation of aorta, Hirschprung's disease, Unilateral renal agenesis, or Craniosynostosis.

- Prevalence non-chromosomal syndromes
  ICD/BPA9: 755.80-755.81, 756.03-756.06, 756.11, 756.40- 756.44, 756.50-756.58, 756.80, 756.85, 7595, 759.60-759.68, 759.8, 279.10-279.11
  ICD10: Q6190, Q743, Q7484, Q770-Q778, Q780-Q784, Q796, Q7982, Q850-Q858, Q87, Q860-Q862, Q992, D821

- Prevalence malformed fetal deaths calculated using total births.

Accuracy of Diagnosis

- % of possible multiple malformations in database excluding chromosomal or syndrome cases using the EUROCAT flow-chart for multiple malformations

- % fetal deaths and terminations of pregnancy with post-mortem examination performed

- % of chromosomal cases with a karyotype performed

- % of non-chromosomal / non-syndrome multiple malformation cases in database with known karyotype. Using the EUROCAT flow-chart for multiple malformations

- Prevalence of selected Q-BPA extension codes (restricted to registries that use ICD10 coding).

Selected Q-BPA codes = Q00.00, Q00.20, Q04.00, Q04.35, Q21.10, Q21.21, Q25.10, Q25.11, Q26.20, Q33.80, Q37.10, Q39.11, Q44.20, Q61.41, Q64.20, Q71.31, Q89.80

- Prevalence of selected Q-chapter unspecified codes (restricted to registries that use ICD10 coding).
  Selected unspecified codes = Q04.9, Q05.9, Q24.9, Q33.9, Q43.9, Q54.9, Q63.9, Q74.9, Q79.9, Q89.9, Q99.9

Completeness of information

Completeness of information describes the amount of **complete valid data** transmitted to Central Registry (eg. "Not known" values, invalid values, or missing/blank fields are counted as incomplete information).

- There are 7 core variables (Sex, Nbrbaby, Type, Weight, Gestlength, Survival, Agemo).

- There are 39 non-core variables (Place, Birthord, Nbrmalf, Death_date, Datedisc, Whendisc, Agedisc, Condisc, Amnio, Chorvilsam, Othertech, Karyo, PM, Datemo, Residmo, SA, IA, LB, SB, Totpreg, Occupmo, Assconcept, Illbef, Illdur1, Habit1, Unusexp, Drugs1, Datefa, Agefa, Occupfa, Mckusick, Modetrans, Consang, Prevsib, Sib1, Sibanom, Moanom, Faanom)

- Written text for syndrome and malformations

Data Quality Indicators 2000-2004 (Created April 2007)

	EUROCAT Average	Hainaut	Odense	Paris	Tuscany	Dublin	N Netherlands	Emilia Romagna	Strasbourg	Vaud	Zagreb	Malta	N E Italy
Ascertainment													
Total No of cases		1678	667	6897	2962	2247	2125	2713	1313	1363	438	642	4085
Total congenital malf prevalence	**225.9**	272.5	249.4	355.2	217.4	197.8	211.3	192.8	326.1	382.3	156.4	324.2	174.7
Spina bifida/Anencephaly ratio	**1.34**	1.74	1.46	0.79	2.67	1.46	2.00	1.79	0.92	1.40	1.00	3.33	2.38
NTD prevalence	**9.7**	9.1	12.7	13.4	5.1	8.7	6.6	7.3	12.7	13.2	5.4	8.6	5.2
Selected cardiac prevalence	**11.8**	12.8	14.6	17.7	10.6	15.3	16.2	13.9	16.9	14.0	8.6	16.7	6.4
Selected postnatal diagnosis prev	**8.9**	14.8	10.8	14.3	8.1	14.8	12.8	11.7	19.6	16.8	5.0	11.6	5.7
Non-chromosomal syndrome prev	**7.7**	13.6	12.0	14.7	5.3	10.0	10.9	9.9	12.9	20.2	2.9	13.6	4.8
Prev malformed SB 20-27 weeks	**1.77**	0.97	1.12	1.39	1.47	1.85	1.59	0.07	2.98	1.40	0.71	2.02	0.09
Prev malformed SB >=28 weeks	**2.68**	1.79	4.86	3.50	0.95	8.80	6.27	0.85	1.74	3.37	1.07	6.56	0.43
% missing SB gestational age	**3**	11	0	0	3	0	3	19	0	0	29	0	8
Accuracy of Diagnosis													
% MM among non-synd/non-chrom	**14.1**	11.6	9.5	10.3	12.8	10.5	15.4	15.0	18.6	15.3	9.7	17.0	16.3
% SB with PM carried out	**42**	58	50	-	59	48	65	38	90	82	57	71	23
% SB with PA (results known)	**34**	58	50	-	50	48	64	38	90	77	43	71	8
% TOP with PM carried out	**36**	61	49	-	44	Illegal	42	39	84	77	14	Illegal	60
% TOP with PM (results known)	**31**	61	48	-	34	Illegal	40	39	82	77	10	Illegal	21
Chrom with karyo carried out	**52**	95	100	-	85	68	100	99	99	100	72	93	85
% Chrom with karyo (results known)	**49**	95	100	-	85	67	100	99	99	100	57	91	45
% Chrom with karyo text#	**43**	88	94	-	65	67	99	-	97	100	55	91	-
% Non-chrom MM with known karyo#	**90**	96	91	-	56	99	99	-	100	101	100	113	-
% DS with CHD or duod atresia (LB)	**27**	24	34	15	11	52	26	16	30	25	49	82	30

Prev selected Q-BPA extension codes	**12.3**	23.1	30.7	33.4	4.6	5.4	8.6	7.4	5.2	37.6	5.0	45.4	-
Prev of selected unspecified Q codes	**9.4**	4.9	1.9	11.5	4.2	11.9	0.8	2.9	0.5	9.0	4.6	4.5	-
Completeness of Information													
No. core variables 90% complete (total=7)	**3**	6	7	6	6	6	7	7	7	7	7	7	2
No. non-core variables 80% complete (total=39)	**2**	18	32	1	19	12	21	20	22	27	27	28	3
% syndomre text complete	**34**	100	99	-	24	100	4	-	100	100	100	0	-
% malfo1 text complete	**56**	100	100	-	22	100	99	-	100	100	100	100	-
No “Other” text information	**8**			X				X					X
Timeliness (Full Members)													
2005 data transmission by 15-02-07	**7**					X							
Denominator Information													
80% of Maternal age denoms by 5yr groups 00-04	**21**		X	X	X	X	X	X		X	X	X	
Availability monthly denoms 2000-2004	**11**			X	X		X	X		X	X	X	

“-“ indicates no data available
some registries code “NOT KNOWN” for karyotype testing, yet have specified the karyotype text information in the SP_KARYO variable field
“X” indicates registry fulfils DQI criteria

	EUROCAT Average	S Portugal	Antwerp	Basque Country	Saxony Anhalt	Mainz	Barcelona	Styria	North Thames	Cork & Kerry	Sicily	Campania	Wales
Ascertainment													
Total No of cases		934	2327	1728	2953	868	982	1824	3073	935	1263	3382	5843
Total congenital malf prevalence	**225.9**	100.6	260.9	187.1	331.7	558.2	186.3	349.5	130.2	226.8	266.3	119.4	373.5
Spina bifida/Anencephaly ratio	**1.34**	1.03	2.27	0.78	2.63	3.00	0.76	3.33	0.98	1.59	6.50	0.90	1.18
NTD prevalence	**9.7**	6.8	8.4	10.9	11.2	24.4	9.5	9.8	11.7	11.2	3.2	6.6	16.1
Selected cardiac prevalence	**11.8**	7.8	15.1	13.1	13.6	24.4	15.0	19.2	10.5	14.1	20.2	6.3	16.5
Selected postnatal diagnosis prev	**8.9**	4.3	15.8	10.9	11.6	22.5	16.9	25.1	5.3	9.2	4.8	4.5	17.3
Non-chromosomal syndrome prev	**7.7**	3.1	11.3	5.2	10.8	28.3	6.3	18.4	5.8	9.2	3.4	2.5	15.8
Prev malformed SB 20-27 weeks	**1.77**	2.37	2.58	0.11	2.58	10.29	0.95	3.26	3.69	1.94	-	-	4.16
Prev malformed SB >=28 weeks	**2.68**	1.83	3.25	1.08	1.57	5.79	5.31	1.72	5.08	8.00	-	0.21	3.26
% missing SB gestational age	**3**	0	2	0	3	4	8	0	0	2	-	25	0
Accuracy of Diagnosis													
% MM among non-synd/non-chrom	**14.1**	20.4	15.0	13.4	23.5	7.9	25.3	40.5	17.3	12.9	7.8	12.6	17.3
% SB with PM carried out	**42**	92	34	46	37	58	69	73	48	29	-	50	77
% SB with PA (results known)	**34**	90	21	46	37	58	69	69	48	29	-	50	73
% TOP with PM carried out	**36**	88	40	74	100	86	59	75	36	Illegal	-	38	55
% TOP with PM (results known)	**31**	84	36	74	100	85	59	75	36	Illegal	-	38	52
Chrom with karyo carried out	**52**	96	100	99	96	77	13	96	100	90	2	28	96
% Chrom with karyo (results known)	**49**	93	54	97	96	74	13	94	100	81	2	28	93
% Chrom with karyo text#	**43**	94	54	98	96	69	96	94	100	80	-	-	97
% Non-chrom MM with known karyo#	**90**	102	100	100	100	43	483	100	102	100	-	-	120
% DS with CHD or duod atresia (LB)	**27**	38	29	18	40	39	29	46	17	56	20	27	41

Prev selected Q-BPA extension codes	**12.3**	8.8	8.3	12.8	20.0	10.3	-	22.2	1.7	12.1	-	5.9	24.8
Prev of selected unspecified Q codes	**9.4**	1.3	9.5	1.8	11.8	10.9	-	3.6	2.0	3.9	-	1.3	11.4
Completeness of Information													
No. core variables 90% complete (total=7)	**3**	7	7	7	7	7	4	5	6	7	3	6	5
No. non-core variables 80% complete (total=39)	**2**	25	9	23	12	21	15	12	6	26	4	24	14
% syndomre text complete	**34**	99	100	100	100	41	0	100	100	100	-	-	100
% malfo1 text complete	**56**	99	100	100	100	38	100	100	100	100	-	-	100
No “Other” text information	**8**										X	X	
Timeliness (Full Members)													
2005 data transmission by 15-02-07	**7**		X		X								
Denominator Information													
80% of Maternal age denoms by 5yr groups 00-04	**21**		X	X	X	X	X	X		X			X
Availability monthly denoms 2000-2004	**11**		X	X	X					X			

“-“ indicates no data available
some registries code “NOT KNOWN” for karyotype testing, yet have specified the karyotype text information in the SP_KARYO variable field
“X” indicates registry fulfils DQI criteria

	EUROCAT Average	Norway	Auvergne	Isle de la Reunion	Wielkopolska	Oxford	Wessex	Trent	NorCAS	Hungary	SE Ireland
Ascertainment											
Total No of cases		2561	374	1245	3828	708	2420	6380	3631	8154	478
Total congenital malf prevalence	**225.9**	441.6	279.2	212.8	224.2	132.9	184.8	216.2	242.4	239.0	191.7
Spina bifida/Anencephaly ratio	**1.34**	1.00	1.33	1.22	2.95	0.92	0.88	1.38	1.23	1.65	2.75
NTD prevalence	**9.7**	11.4	8.2	11.5	10.4	10.7	13.8	11.2	14.0	6.9	12.0
Selected cardiac prevalence	**11.8**	2.1	12.7	10.4	10.4	9.0	15.6	12.2	19.1	11.5	13.2
Selected postnatal diagnosis prev	**8.9**	1.4	7.5	12.0	4.9	3.4	10.7	6.9	11.4	5.9	9.6
Non-chromosomal syndrome prev	**7.7**	1.2	15.7	15.96	2.9	11.1	10.5	7.6	13.6	2.6	7.2
Prev malformed SB 20-27 weeks	**1.77**	0.35	2.24	1.54	1.00	2.07	4.89	4.30	2.60	0.56	2.00
Prev malformed SB >=28 weeks	**2.68**	0.62	4.48	2.91	1.05	3.57	5.88	4.27	3.61	0.59	16.04
% missing SB gestational age	**3**	0	0	0	13	0	1	6	0	20	0
Accuracy of Diagnosis											
% MM among non-synd/non-chrom	**14.1**	6.9	16.5	17.3	16.0	10.9	12.2	13.5	11.7	9.5	11.0
% SB with PM carried out	**42**	-	89	19	-	47	68	-	61	-	60
% SB with PA (results known)	**34**	-	89	19	-	0	0	-	61	-	58
% TOP with PM carried out	**36**	-	81	21	-	36	48	-	58	-	Illegal
% TOP with PM (results known)	**31**	-	81	19	-	0	0	-	58	-	Illegal
Chrom with karyo carried out	**52**	-	100	98	83	3	-	-	-	-	50
% Chrom with karyo (results known)	**49**	-	100	98	81	0	-	-	-	-	48
% Chrom with karyo text#	**43**	-	-	98	82	-	-	-	24	-	48
% Non-chrom MM with known karyo#	**90**	-	0	98	97	-	-	-	-	-	100
% DS with CHD or duod atresia (LB)	**27**	36	48	26	44	15	18	21	35	28	67

Prev selected Q-BPA extension codes	**12.3**	0.0	9.7	21.0	0.0	0.0	0.0	0.4	23.0	0.0	6.4
Prev of selected unspecified Q codes	**9.4**	5.1	14.2	1.2	13.3	5.6	6.3	24.6	10.1	25.6	6.0
Completeness of Information											
No. core variables 90% complete (total=7)	**3**	6	6	7	6	6	5	4	7	4	7
No. non-core variables 80% complete (total=39)	**2**	1	13	26	9	5	7	1	17	0	10
% syndomre text complete	**34**	100	100	100	-	100	-	100	100	-	99
% malfo1 text complete	**56**	0	0	100	-	100	100	100	100	-	100
No “Other” text information	**8**	X	X						X		
Timeliness (Full Members)											
2005 data transmission by 15-02-07	**7**	X				X	X		X		
Denominator Information											
80% of Maternal age denoms by 5yr groups 00-04	**21**	X				X	X	X			
Availability monthly denoms 2000-2004	**11**										

“-“ indicates no data available
some registries code “NOT KNOWN” for karyotype testing, yet have specified the karyotype text information in the SP_KARYO variable field
“X” indicates registry fulfils DQI criteria

Appendix 3
EUROCAT Guide 1.3 and Reference Documents "Instructions for the Registration and Surveillance of Congenital Anomalies"

www.eurocat.ulster.ac.uk/pdf/EUROCAT-Guide-1.3.pdf

Appendix 4
EUROCAT Guide 6 (2004) "Definition and Coding of Syndromes"

www.eurocat.ulster.ac.uk/pdf/Ester/EUROCAT-Guide-6-Version-3.pdf

Appendix 5
EUROCAT Guide 3 (2nd Edition) (2004) "For the Description and Classification of Congenital Limb Defects"

www.eurocat.ulster.ac.uk/pdf/EUROCAT-Final-Guide-3.pdf

Appendix 6a
EUROCAT Statistical Monitoring Protocol

www.eurocat.ulster.ac.uk/pdf/EUROCAT-Statistical-Monitoring-Protocol-Draft.pdf

Appendix 6b
EUROCAT Statistical Monitoring Report 2004

www.eurocat/ulster.ac.uk/pdf/Statistical-Monitoring-Report-2004.pdf

Appendix 7
EUROCAT Special report (2005) "Prevention of Neural Tube Defects by Periconceptional Folic Acid Supplementation in Europe"

www.eurocat.ulster.ac.uk/pubdata/Folic-Acid.html

Appendix 8
EUROCAT Special Report (2005) "Prenatal Screening Policies in Europe"

www.eurocat.ulster.ac.uk/pdf/Special-Report-Prenatal-Diagnosis.pdf

Appendix 9
Selected EUROCAT Publications/Abstracts

Calzolari E, Bianchi F, Rubini M, Ritvanen A, Neville A and a EUROCAT Working Group (2004), "Epidemiology of Cleft Palate in Europe: Implications for Genetic Research Strategy", *The Cleft Palate-Craniofacial Journal*, Vol 41, No 3, pp 244-249

Objective: To describe the epidemiology of cleft palate (CP) in Europe.

Design and Setting: A descriptive epidemiological study on 3852 cases of CP, identified (1980 through 1996) from more than 6 million births from the EUROCAT network of 30 registers in 16 European countries.

Results: Significant differences in prevalence in Europe between registries and within countries were observed. A total of 2112 (54.8%) CP cases occurred as isolated, 694 (18.0%) were associated with other defects such as multiple congenital anomalies, and 1046 (27.2%) were in recognized conditions. The study confirmed the tendency toward female prevalence (sex ratio [SR] = 0.83), particularly among isolated cases (SR = 0.78) even if SR inversion is reported in some registries. A specific association with neural tube defects (NTDs) in some registers is reported.

Conclusion: The differences identified in Europe (prevalence, sex, associated anomalies) can be only partially explained by methodological reasons because a common methodology was shared among all registries for case ascertainment and collection, and CP is an easy detectable condition with few induced abortions. The complex model of inheritance and the frequently conflicting results in different populations on the role of genes that constitute risk factors suggest the presence of real biological differences. The association of CP/NTD in an area with a high prevalence of NTDs can identify a group of conditions that can be considered etiologically homogeneous. The epidemiological evaluation can guide genetic research to specify the role of etiological factors in each different population.

Dolk H, Vrijheid, Scott JES, Addor MC, Botting B, de Vigan C, de Walle H, Garne E, Loane M, Pierini A, Garcia-Minaur S, Physick N, Tenconi R, Wiesel A, Calzolari E & Stone D (2004), "Towards the Effective Surveillance of Hypospadias", *Environmental Health Perspectives*, Vol 112, No 3, pp 398-402

Concern about apparent increases in the prevalence of hypospadias-a congenital male reproductive-tract abnormality-in the 1960s to 1980s and the possible connection to increasing exposures to endocrine-disrupting chemicals have underlined the importance of effective surveillance of hypospadias prevalence in the population. We report here the prevalence of hypospadias from 1980 to 1999 in 20 regions of Europe with EUROCAT (European Surveillance of Congenital Anomalies) population-based congenital anomaly registers, 14 of which implemented a guideline to exclude glanular hypospadias. We also report data from the England and Wales National Congenital Anomaly System (NCAS). Our results do not suggest a continuation of rising trends of hypospadias prevalence in Europe. However, a survey of the registers and a special validation study conducted for the years 1994-1996 in nine EUROCAT registers as well as NCAS identified a clear need for a change in the guidelines for registration of hypospadias. We recommend that all hypospadias be included in surveillance, but that information from surgeons be obtained to verify location of the meatus, and whether surgery was performed, in order to interpret trends. Investing resources in repeated special surveys may be more cost-effective than continuous population

surveillance. We conclude that it is doubtful whether we have had the systems in place worldwide for the effective surveillance of hypospadias in relation to exposure to potential endocrine-disrupting chemicals. Key words: endocrine-disrupting chemicals, Europe, hypospadias, prevalence, surveillance. Environ Health Perspect 112:398-402 (2004). doi:10.1289/ehp.6398 available via http://dx.doi.org/[Online 18 November 2003]

Boyd PA, Armstrong A, Dolk H et al (2005), "Congenital Anomaly Surveillance in England: Ascertainment Deficiencies in the National System", *British Medical Journal*, Vol 330, No 7481, pp 27

Objective: Firstly, to assess the completeness of ascertainment in the National Congenital Anomaly System (NCAS), the basis for congenital anomaly surveillance in England and Wales, and its variation by defect, geographical area, and socioeconomic deprivation. Secondly, to assess the impact of the lack of data on pregnancies terminated because of fetal anomaly.

Design: Comparison of the NCAS with four local congenital anomaly registers in England.

Setting: Four regions in England covering some 109 000 annual births.

Participants: Cases of congenital anomalies registered in the NCAS (live births and stillbirths) and independently registered in the four local registers (live births, stillbirths, fetal losses from 20 weeks' gestation, and pregnancies terminated after prenatal diagnosis of fetal anomaly).

Main outcome measure: The ratio of cases identified by the national register to those in local registry files, calculated for different specified anomalies, for whole registry areas, and for hospital catchment areas within registry boundaries.

Results: Ascertainment by the NCAS (compared with data from local registers, from which terminations of pregnancy were removed) was 40% (34% for chromosomal anomalies and 42% for non-chromosomal anomalies) and varied markedly by defect, by local register, and by hospital catchment area, but not by area deprivation. When terminations of pregnancy were included in the register data, ascertainment by NCAS was 27% (19% for chromosomal anomalies and 31% for non-chromosomal anomalies), and the geographical variation was of a similar magnitude.

Conclusion: The surveillance of congenital anomalies in England is currently inadequate because ascertainment to the national register is low and non-uniform and because no data exist on termination of pregnancy resulting from prenatal diagnosis of fetal anomaly.

Busby A, Armstrong B, Dolk H, Armstrong N, Haeusler M, Berghold A, Gillerot Y, Baguette A, Gjergja R, Barisic I, Christiansen M, Goujard J, Steinbicker V, Roesch C, McDonnell R, Scarano G, Calzolari E, Neville A, Cocchi G, Bianca S, Gatt M, de Walle H, Braz P, Latos-Bielenska A, Gener B, Portillo I, Addor M-C, Abramsky L, Ritvanen A, Robert-Gnansia E, Daltveit, A, Aneren G, Ollars B, Edwards G (2005), "Preventing Neural Tube Defects in Europe: A Missed Opportunity", *Reproductive Toxicology*, Vol 20, No 3, pp 393-402

Each year, more than 4500 pregnancies in the European Union are affected by neural tube defects (NTD). Unambiguous evidence of the effectiveness of periconceptional folic acid in preventing the majority of neural tube defects has been available since 1991. We report on trends in the total prevalence of neural tube defects up to 2002, in the context of a survey in 18 European countries of periconceptional folic acid supplementation (PFAS) policies and their implementation. EUROCAT is a network of population-based registries in Europe collaborating in the epidemiological surveillance of congenital anomalies. Representatives from 18 participating countries provided information about policy, health education campaigns and surveys of PFAS uptake. The yearly total prevalence of neural tube defects including livebirths, stillbirths and terminations of pregnancy was calculated from 1980 to 2002 for 34 registries, with UK and Ireland estimated separately from the rest of Europe. A meta-analysis of changes in NTD total prevalence between 1989?1991 and 2000?2002 according to PFAS policy was undertaken for 24 registries. By 2005, 13 countries had a government recommendation that women planning a pregnancy should take 0.4mg folic acid supplement daily, accompanied in 7 countries by government-led health education initiatives. In the UK and Ireland, countries with PFAS policy, there was a 30% decline in NTD total prevalence (95% CI 16?42%) but it was difficult to distinguish this from the pre-existing strong decline. In other European countries with PFAS policy, there was virtually no decline in NTD total prevalence whether a policy was in place by 1999 (2%, 95% CI 28% reduction to 32% increase) or not (8%, 95% CI 26% reduction to 16% increase). The potential for preventing NTDs by periconceptional folic acid supplementation is still far from being fulfilled in Europe. Only a public health policy including folic acid fortification of staple foods is likely to result in large-scale prevention of NTDs.

Busby A, Abramsky L, Dolk H, Armstrong B and a EUROCAT Folic Acid Working Group (2005), "Preventing Neural Tube Defects in Europe: Population Based Study", *British Medical Journal*, Vol 330, pp 574-575.

Each year, more than 4500 pregnancies in the European Union are affected by neural tube defects. Unambiguous evidence of the effectiveness of periconceptional folic acid in preventing neural tube defects has been available since 1991,1 and improving folate status sufficiently could result in the prevention of more than two thirds of all neural tube defects. We report on trends in the prevalence of neural tube defects up to 2001, in the context of a survey in 16 European countries of periconceptional folic acid policies and their implementation.

Busby A, Armstrong B, Dolk H et al (2005), "Preventing Neural Tube Defects in Europe: A Missed Opportunity", *Reproductive Toxicology*, Vol 20, pp 393-402.

Each year more than 4,500 pregnancies in the European Union are affected by neural tube defects (NTD). Unambiguous evidence of the effectiveness of perinconceptional folic acid in preventing the majority of neural tube defects has been available since 1991. We report on trends in the total prevalence of neural tube defects up to 2002, in the context of a survey in 18 European countries of periconceptional folic acid supplementation (PFAS) policies and their implementation. EUROCAT is a network of population-based registered in Europe collaborating in the epidemiological surveillance of congenital anomalies. Representatives from 18 participating countries provided information about policy, health education campaigns and surveys of PFAS uptake. The yearly total prevalence of neural tube defects including livebirths, stillbirths and terminations of pregnancy was calculated from 1980-2002 for 34 registries, with UK and Ireland estimated separately from the rest of Europe. A meta-analysis of changes in NTD total prevalence between 1989-1991 and 2000-2002 according to PFAS policy was undertaken for 24 registries. By 2005, 13 countries had a government recommendation that women planning a pregnancy should take 0.4 mg folic acid supplement daily, accompanied in 7 countries by government-led health education initiatives. In the UK and Ireland, countries with PFAS policy, there was a 30% decline in NTD total prevalence (95% CI 16-42%) but it was difficult to distinguish this from the pre-existing strong decline. In other European countries with PFAS policy, there was virtually no decline in NTD total prevalence whether a policy was in place by 1999 (2%, 9% CI 28% reduction to 32% increase) or not (8%, 95% CI 26% reduction to 16% increase). The potential for preventing NTDs by periconceptional folic acid supplementation is still far from being fulfilled in Europe. Only a public health policy including folic acid fortification of staple foods in likely to result in large-scale prevention of NTDs.

Busby A, Ritvanen A, Dolk H, Armstrong N, De Walle H, Riano-Galan I, Gatt M, McDonnell R, Nelen V and Stone D (2005), "Survey of Informed Consent for Registration of Congenital Anomalies in Europe", *British Medical Journal,* Vol 331, pp 140-41.

EUROCAT is a network of population based registers of congenital anomalies in Europe covering about a quarter of the birth population in 19 countries (www.eurocat.ulster.ac.uk). We surveyed registries with regard to the requirement for informed consent and its implementation.
We sent a questionnaire on ethics and confidentiality developed by the EUROCAT Working Group to 35 registries in 2003 and updated June 2004; 29 registries from 15 countries replied (table). Eight registries reported experience of opt-in informed consent

Dolk H et al (2005), "EUROCAT: 25 Years of European Surveillance of Congenital Anomalies", *Archives of Disease in Childhood,* Vol 90, No 5, pp F355-F358.

The surveillance of congenital anomalies serves two main purposes: to facilitate the identification of teratogenic (malformation causing) exposures and to assess the impact of primary prevention and prenatal screening policy and practice at a population level. EUROCAT, the European network of population based registers for the epidemiological surveillance of congenital anomalies, now covers 1.2 million births per year, a quarter of births in Europe. The added value of European collaboration is particularly great for congenital anomalies, coming from the opportunity to pool data, to compare data between regions and countries, to give a common response to European public health questions, and to

share expertise and resources, including computing tools. EUROCAT provides essential epidemiological information on congenital anomalies in Europe, facilitates the early warning of teratogenic exposures, evaluates the effectiveness of primary prevention, assesses the impact of developments in prenatal screening, acts as an information and resource centre regarding clusters, provides a ready collaborative network and infrastructure for research, and acts as a catalyst for the setting up of registries throughout Europe.

Dolk H, Loane M, Garne E, de Walle, H, Queisser-LuftA, de Vigan C, Addor M-C, Gener B, Haeusler M, Jordan H, Tucker D, Stoll C, Feijoo M, Lillis D, Bianchi F (2005), "Trends and Geographic Inequalities in the Livebirth Prevalence of Down Syndrome in Europe 1980-1999", *Revues Epidem Sante Publique*, Vol 53, pp 2S87-2S95

Background: EUROCAT is a network of population-based registries for the epidemiologic surveillance of congenital anomalies covering approximately one quarter of births in the European Union. Down syndrome constitutes approximately 8% of cases of registered congenital anomaly in Europe, with over 7000 affected pregnancies in the 15 current member states of the European Union each year. In this paper, we aim to examine trends in the live birth prevalence of Down syndrome in Europe in the light of trends in maternal age and in prenatal diagnosis.

Methods: Descriptive analysis of data from 24 EUROCAT registries, covering 8.3 million births 1980-99. Cases include live births, stillbirths and terminations of pregnancy following prenatal diagnosis.

Results: Since 1980, the proportion of births to mothers of 35 years of age and over has risen quite dramatically from 8 to 14% for the European Union as a whole, with steeper rises in some regions. By 1995-1999, the proportion of 'older' mothers varied between regions from 10% to 25%, and the total prevalence (including terminations of pregnancy) of Down syndrome varied from 1 to 3 per 1000 births. Some European regions have shown a more than twofold increase in total prevalence of Down syndrome since 1980. The proportion of cases of Down syndrome which were prenatally diagnosed followed by termination of pregnancy is 1995-1999 varied from 0% in the three regions of Ireland and Malta where termination of pregnancy is illegal, to less than 50% in 14 further regions, to 77% in Paris. The extent to which terminations of pregnancy were concentrated among older mothers varied between regions. The live birth prevalence has since 1980 increasingly diverged from the rising total prevalence, in some areas remaining approximately stable, in others decreasing over time.

Conclusion: The rise in average maternal age in Europe has brought with it an increase in the number of pregnancies affected by Down syndrome. The widespread practice of prenatal screening and termination of pregnancy has in most of the regions covered by EUROCAT counteracted the effect of maternal age in its effect on live birth prevalence. Under the joint influences of maternal age and prenatal screening the pattern of geographic inequalities in Down syndrome live birth prevalence in Europe has also been changed.

Garne E, Loane M, Dolk H and a EUROCAT Working Group (2005), "Prenatal Diagnosis of Severe Structural Congenital Malformations in Europe", *Ultrasound Obstet Gynecol*, Vol 25, pp 6-11.

Objectives: To assess at a population-based level the frequency with which sever structural congenital malformations are detected prenatally in Europe and the gestational age at detection, and to describe regional variation in these indicators.

Methods: In the period 1995-1999, data were obtained from 17 European population-based registries of congenital malformations (EUROCAT). Included were all live births, fetal deaths and terminations of pregnancy diagnosed with one or more of the following malformations: anencephalus, encephalocele, spina bifida, hydrocephalus, transposition of great arteries, hypoplastic left heart, limb reduction defect, bilateral renal agenesis, diaphragmatic hernia, omphalocele and gastroschisis.

Results: the 17 registries report 4,266 cases diagnosed with the 11 severe structural malformations and of these 2,300 were live births (53%), 181 were fetal deaths (4%) and 1,863 were terminations of pregnancy (43%); in 22 cases pregnancy outcome was unknown. The overall prenatal detection rate was 64% (range 25-88% across regions). The proportion of terminations of pregnancy varied between regions from 15% to 59% of all cases. Gestational age at discovery for prenatally diagnosed cases was less than 24 weeks for 68% (range 36-88%) of cases. There was a significant relationship between high prenatal detection rate and early diagnosis ($P < 0.0001$). For individual malformations, the prenatal detection rate was highest for anencephalus (469/498, 94%) and lowest for transposition of the great arteries (89/324, 27%). Termination of pregnancy was performed in more that half of the prenatally diagnosed cases, except for those with transposition of the great arteries. Diaphragmatic hermia and gastroschisis, in which 30-40% of the pregnancies with a prenatal diagnosis were terminated.

Conclusion: European countries currently vary widely in the provision and uptake of prenatal screening and its quality, as well as the "culture" in terms of decision to continue the pregnancy. This inevitably contributes to variation between countries in perinatal and infant mortality and in childhood prevalence and cost to health services of congenital anomalies.

Morris JK, de Vigan C, Mutton DE, Alberman E (2005), "Risk of a Down Syndrome Live Birth in Women of 45 Years of Age and Older", *Prenatal Diagnosis*, Vol 25, pp 275-278

To determine the risk of a Down Syndrome (DS) live birth for women 45 years of age and over.

A meta-analysis of data from five published articles, 13 EUROCAT congenital anomaly population registers and two unpublished sources.

Information was available on the number of DS live births occurring amongst 13,745 live births to women 45 years of age and over. Information was also available on DS pregnancies diagnosed prenatally that were subsequently terminated. These pregnancies were adjusted for expected fetal loss to estimate the number of live births that would have occurred in the absence of prenatal diagnosis, when a total of 471 DS live births were estimated to have occurred. The risk of a DS birth did no increase for women 45 years of age and over. The average risk was 34 per 1,000 births (95% CI: 31-37).

The risk of a DS live birth for women 45 years of age and over is considerably lower than has often been previously assumed. The most likely explanation is that women of this age are more likely to miscarry DS pregnancies than younger mothers.

Rankin J, Pattenden S, Abramsky L, Boyd P, Jordan H, Stone D, Vrijheid M, Wellesley D and Dolk H (2005), "Prevalence of Congenital Anomalies in Five British Regions, 1991-99", *Archive Dis Child Fetal Neonatal*, Vol 90, pp 374-379

Aims: To describe trends in total and live birth prevalence, regional differences in prevalence, and outcome of pregnancy of selected congenital anomalies.
Methods: Population based registry study of 839 521 births to mothers resident in five geographical areas of Britain during 1991–99. Main outcome measures were: total and live birth prevalence; pregnancy outcome; proportion of stillbirths due to congenital anomalies; and secular trends.
Results: The sample consisted of 10 844 congenital anomalies, giving a total prevalence of 129 per 10 000 registered births (95% CI 127 to 132). Live birth prevalence was 82.2 per 10 000 births (95% CI 80.3 to 84.2) and declined significantly with time. The proportion of all stillbirths with a congenital anomaly was 10.5% (453 stillbirths). The proportion of pregnancies resulting in a termination increased from 27% (289 cases) in 1991 to 34.7% (384 cases) in 1999, whereas the proportion of live births declined from 68.2% (730 cases) to 58.5% (648 cases). Although similar rates of congenital anomaly groups were notified to the registers, variation in rates by register was present. There was a secular decline in the total prevalence of non-chromosomal and an increase in chromosomal anomalies.
Conclusions: Regional variation exists in the prevalence of specific congenital anomalies. For some anomalies this can be partially explained by ascertainment variation. For others (neural tube defects, diaphragmatic hernia, gastroschisis), higher prevalence rates in the northern regions (Glasgow and Northern) were true differences. Live birth prevalence declined over the study due to an increase in terminations of pregnancy.

Dobson R (2006), "Rise in Maternal Age has Led to Increase in Pregnancies Affected by Down's Syndrome", *BMJ*, Vol 332, pp 1234

Increases in the numbers of older mothers has led to a rise in the number of pregnancies affected by Down's syndrome in Europe.
Some European regions have shown a more than twofold increase in total prevalence of Down's syndrome since 1980, say researchers from the European Surveillance of Congenital Anomalies, a network of population-based registries for the epidemiological surveillance of congenital anomalies covering around one quarter of births in the European Union.
According to the report in *Revue d'épidémiologie et de santé publique* (2005; 53: 2587-95), Down syndrome makes up around 8% of cases of registered congenital anomaly in Europe, with more than 7000 affected pregnancies in the 15 current member states of the European Union each year.
In the research, at the network's central registry at the University of Ulster, data from 24 registries covering 8.3 million births between 1980-99, including live births, stillbirths and terminations of pregnancy following prenatal diagnosis, were analysed.
The analysis shows that since 1980, the proportion of births to older mothers (35 years of age and over) compared to all births has risen from 8% to 14% for the European Union as a whole, with steeper rises in some regions.

Meijer W, Cornel MC, Dolk H, de Walle HEK, Armstrong NC, de Jong-van den Berg LTW and a EUROCAT Working Group (2006), "The Potential of the European Network on Congenital Anomaly Registers (EUROCAT) for Drug Safety Surveillance: A Descriptive Study", *Pharmacoepdemiology and Drug Safety*, Vol 15, pp 675-682

European Surveillance of Congenital Anomalies (EUROCAT) is a network of population-based congenital anomaly registries in Europe surveying more than 1 million births per year, or 25% of the births in the European Union. This paper describes the potential of the EUROCAT collaboration for pharmacoepidemiology and drug safety surveillance.
Methods: The 34 full members and 6 associate members of the EUROCAT network were sent a questionnaire about their data sources on drug exposure and on drug coding. Available data on drug exposure during the first trimester available in the central EUROCAT database for the years 1996-2000 was summarised for 15 out of 25 responding full members.
Results: Of the 40 registries, 29 returned questionnaires (25 full and 4 associate members). Four of these registries do not collect data on maternal drug use. Of the full members, 15 registries use the EUROCAT drug code, 4 use the international ATC drug code, 3 registries use another coding system and 7 use a combination of these coding systems. Obstetric records are the most frequently used sources of drug information for the registries, followed by interviews with the mother. Only one registry uses pharmacy data. Percentages of cases with drug exposure (excluding vitamins/minerals) varied from 4.4% to 26.0% among different registries. The categories of drugs recorded varied widely between registries.
Conclusions: Practices vary widely between registries regarding recording drug exposure information. EUROCAT has the potential to be an effective collaborative framework to contribute to post-marketing drug surveillance in relation to teratogenic effects, but work is needed to implement ATC drug coding more widely, and to diversify the sources of information used to determine drug exposure in each registry.

Abramsky L, Dolk H and a EUROCAT Folic Acid Working Group (2007) "Should Europe Fortify a Staple Food with Folic Acid?" *The Lancet*, Vol 369, pp 641-642

There is a large body of evidence that periconceptional folic acid protects against the occurrence of lethal anencephaly and disabling spina bifida, which are collectively known as neural tube defects (NTDs) and which affect more than 4,000 fetuses or babies in Europe each year. In most countries in Europe, women planning a pregnancy are advised to take 0.4 mg folic acid daily starting before conception and throughout the first trimester of pregnancy. However, most do not take folic acid supplementation before conception, and the hoped-for dramatic decline in NTD rates has failed to materialise. Many countries, particularly those of North and South America, have introduced mandatory fortification of flour with folic acid, and have enjoyed a reduction in NTD rates.

There have been moves towards fortification of flour in several European countries, but to date this has not been implemented. The main obstacle has been the concern that the known benefit of folic acid fortification to the few (women who become pregnant) and the potential benefits to the many (for example, the possible prevention of cardiovascular disease) might be outweighed by some as-yet-unknown risk for the general population. The general public and all stakeholders should be involved in determining this balance. Patients' or parents' organisations, who represent those most knowledgeable about the effect of NTDs on individuals and families, are key stakeholders.

At the beginning of 2006, the EUROCAT (organisation for European Surveillance of Congenital Anomalies) Folic Acid Working Group sent out a brief questionnaire to

representatives of NTD support groups in 25 countries across Europe. We asked what their position was regarding mandatory fortification of a staple food with folic acid and what they were doing about it. We received (after one reminder) replies from groups in 12 countries: Austria, Belgium, Croatia, Denmark, France, Ireland, Italy, the Netherlands, Portugal, Slovakia, Turkey and the UK. It is plausible that the groups who did not reply were less interested in the issue of fortification, but this is not possible to verify

10 of the 12 groups were in favour of mandatory fortification of a staple food (usually flour) with folic acid. The other two, in the Netherlands and Italy, preferred voluntary fortification. Half of the ten groups in favour of mandatory fortification said that they were actively campaigning for it and half said they were not actively campaigning: three due to lack of resources, one because they were too busy with other problems, and one because they were still in the process of planning a campaign.

We found that NTD support groups in Europe are generally in favour of mandatory fortification of flour with folic acid.

Barisic I, Tokiv V, Loane M, Bianchi F, Calzolari E, Garne E, Wellesley D, Dolk H and a EUROCAT Working Group (in press), "Descriptive Epidemiology of Cornelia de Lange Syndrome in Europe", ***American Journal of Medical Genetics***

Cornelia de Lange syndrome (CdLS) is a multiple congenital anomaly/mental retardation syndrome consisting of characteristic dysmorphic features, microcephaly, hypertrichosis, upper limb defects, growth retardation, developmental delay, and a variety of associated malformations. We present a population-based epidemiological study of the classical form of CdLS. The data were extracted from the database of European Surveillance of Congenital Anomalies (EUROCAT) database, a European network of birth defect registries which follow a standard methodology. Based on 23 years of epidemiologic monitoring (8,558,346 births in the 1980-2002 period), we found the prevalence of the classical form of CdLS to be 1.24/100,000 births or 1:81,000 births and estimated the overall CdLS prevalence at 1.6-2.2/100,000. Live born children accounted for 91.5% (97/106) of cases, fetal deaths 2.8% (3/106), and terminations of pregnancy following prenatal diagnosis 5.7% (6/106). The most frequent associated congenital malformations were limb defects (73.1%), congenital heart defects (45.6%), central nervous system malformations (40.2%), and cleft palate (21.7%). In the last 11 years, as much as 68% of cases with major malformations were not detected by routine prenatal US. Live born infants with CdLS have a high first week survival (91.4%). All patients were sporadic. Maternal and paternal age did not seem to be risk factors for CdLS. Almost 70% of patients, born after the 37th week of gestation, weighed </=2,500 g. Low birth weight correlated with a more severe phenotype. Severe limb anomalies were significantly more often present in males.

Calzolari E, Pierini A, Astolfi G, Bianchi F, Neville AJ, Rivieri F and the EUROCAT Working Group (2007) "Associated Anomalies in Multi-Malformed Infants with Cleft Lip and Palate: An Epidemiologic Study of Nearly 6 Million Births in 23 EUROCAT Registries", ***American Journal of Medical Genetics Part A,*** **Vol 143, No 6, pp 528-527**

We studied 5,449 cases of cleft lip (CL) with or without cleft palate (CL/P) identified between 1980 and 2000 from the EUROCAT network of 23 Registries (nearly 6 million births) in 14 European countries. We investigated specific types of defect associated with clefts. Among CL/P cases (prevalence = 9.1 per 10,000), 1,996 (36.6%) affected only the lip (CL) and 3,453 (63.4%) involved CL and palate (CLP). A total of 3,860 CL/P cases (70.8%)

occurred as isolated anomalies and 1,589 (29.2%) were associated with other defects such as multiple congenital anomalies of unknown origin (970), chromosomal (455) and recongised syndromes (164). Associated malformations were more frequent in infants who had CLP (34.0%) than in infants with CL only (20.8%). Among multi-malformed infants, 2 unrelated anomalies were found in 351 cases, 3 in 242 cases and 4 or more in 377 cases. Among 5,449 CL/P cases, 4,719 were live births (86.6%), 203 stillbirths (SB) (3.7%), while 508 (9.3%) were terminations of pregnancy (ToP). CL/P occurred significantly more frequently in males (M/F = 1.70), especially among total isolates cases (M/F = 1.87) and CLP isolates cases (M/F = 1.92). The study confirmed that musculoskeletal, cardiovascular, and central nervous systems defects are frequently associated with CL/P. An association with reduction anomalies of the brain was found. This associated suggests that clinicians should seek to identify structural brain anomalies in these patients with CL/P as the potential functional consequences may be important for rehabilitation and clinical management.

Garne E, Loane M, Dolk H and a EUROCAT Working Group (2007), "Gastrointestinal Malformations: Impact of Prenatal Diagnosis on Gestational Age at Birth", *Paediatric and Perinatal Epidemiology*, Vol 21, pp 370-375

The aim of the study was to analyse the degree to which gestation age (GA) has been shortened sue to prenatal diagnosis of gastrointestinal malformations (GIM). The data source for the study was 14 population-based registries of congenital malformations (EUROCAT). All liveborn infants with GIMs and without chromosomal anomalies, born 1997-2002, were included. The 14 Registries identified 1047 liveborn infants with one or more GIMs (oesophageal atresia, duodenal atresia, omphalocele, gastroschisis and diaphragmatic hernia). Median GA at birth was lower in prenatally diagnosed cases for all five malformations, although not statistically significant for gastroschisis. There was little difference in median birthweight by GA for the pre- and postnatally diagnosed infants.

The difference in GA at birth between prenatally and postnatally diagnosed infants with GIMs is enough to increase the risk of mortality for the prenatally diagnosed infants. Clinicians need to balance the risk of early delivery against the benefits of clinical convenience when making case management decisions after prenatal diagnosis. Very few studies have been able to show benefits of prenatal diagnosis of congenital malformations for liveborn infants. This may be because the benefits of prenatal diagnosis are outweighed by the problems arising from a lower GA at birth.

Garne E, Loane M, Nelen V, Bakker M, Gener B, Abramsky L, Addor M-C and Queisser-Luft A (2007), "Survival and Health in Liveborn Infants with Transposition of Great Arteries - A Population Based Study", *Congenital Heart Diseases*, Vol 2, pp 165-169

Objective: To describe treatment, survival and morbidity for liveborn infants with isolated transposition of great arteries (TGA).

Design: Population-based data from 7 European registries of congenital malformations (EUROCAT).

Results: Ninety-seven infants were diagnosed with isolated TGA and livebirth prevalence was 2.0 per 10,000 livebirths. The majority of infants were treated with prostaglandins (83%) and 57% had a catheter atrial septostomia performed. Arterial switch surgery was performed in 78 infants, other or unknown type of surgery was performed in 3 cases, and for 6 infants

there was not information on surgery. At 1 year of age 69 infants were alive (71%0 and 24 (25%) were dead (4 unknown). There were 10 deaths before surgery and 58% of all deaths took place during the first week. There was no statistically significant regional difference in mortality. Eight infants diagnosed prenatally all survived to 1 year and only 71% of infants diagnosed after birth survived ($P = 0.08$). Data on morbidity at 1 year of age was available for 57 infants. Fifty-one infants were reported with normal health and development.

Conclusions: in this population-based study survival for liveborn infants with TGA is lower than in studies published from tertiary centers. Outcome for survivors at 1 year of age seems favourable.

Loane M, Dolk H, Bradbury and a EUROCAT Working Group (2007), "Increasing Prevalence of Gastroschisis in Europe 1980-2002: A Phenomenon Restricted to Younger Mothers?", *Paediatric and Perinatal Epidemiology*, Vol 21, pp 363-369

Gastroschisis is an abdominal wall defect more prevalent in offspring of young mothers. It is known to be increasing in prevalence despite the general decrease in the proportion of birth to young European women. We investigated whether the increase in prevalence was restricted to the high-risk younger mothers. We analysed 936 cases of gastroschisis from 25 population-based registries in 15 European countries, 1980-2002. We fitted a Bayesian Hierarchical Model which allowed us to estimate trend, to estimate which registries were significantly different from the common distribution, and to adjust simultaneously for maternal age, time (in grouped years) and the random variation between registries.

The maternal age-standardised prevalence (standardised to the year 2000 European maternal age structure) increased almost fourfold from 0.54 [95% Credible Interval CrI) 0.37, 0.75] per 10,000 births in 1980-84 to 2.12 [95% CrI 1.85, 2.40] per 10,000 births in 2000-02. The relative risk of gastroschisis for mother <20 years of age in 1995-2002 was 7.0 [95% CrI 5.6, 8.7]. There were geographical differences within Europe, with higher rates of gastroschisis in the UK, and lower rates in Italy after adjusting for maternal age. After standardising for regional variation, our results showed that the increase in risk over time was the same for mothers of all ages – the increase for mothers <20 years was 3.96-fold compared with an increase of 3.95-fold for mothers in the other age groups. These findings indicate that the phenomenon of increasing gastroschisis prevalence is not restricted to younger mothers only.

Loane M, Dolk H, Morris J and a EUROCAT Working Group (2007), Abstract presentated at Society for Social Medicine Confernece in Cork, September 2007, "Maternal Age Specific Risk of non-Chromosomal Anomalies"

Objectives
The increased risk of chromosomal anomalies associated with older mothers is well documented. We assess the risk of non-chromosomal anomalies in older mothers (35+ years) and younger mothers (<20 years) in Europe 1990-2004.

Design and Setting
Prevalence study in 25 regions of Europe covered by population-based EUROCAT registries, 1990-2004, covering a total of 4.8 million births. The EUROCAT database contains standardised comparable data on malformations obtained from a collaborative network of European registries set up to carry out epidemiologic surveillance of congenital anomalies throughout Europe.

Participants
All registered cases of non-chromosomal anomaly that were liveborn, fetal deaths at twenty weeks gestation or more or terminations of pregnancy following prenatal diagnosis of a congenital malformation.

Main Outcome Measures
Prevalence of non-chromosomal anomalies (total cases divided by total births) by 5-year maternal age groups.

Results
In the year 1990-2004, 25 regional registries in 15 European countries identified a total of 111,899 cases of non-chromosomal anomalies with maternal age known, giving a prevalence rate of 23 per 1,000 births. The proportion of young mothers (<20 years) increased from 3% in 1990-1994 to 5% in 2000-2004, while the proportion of older mothers (35+ years) increased from 14% in 1990-1994 to 19% in 2000-2004. The prevalence of all non-chromosomal anomalies was 27 per 1,000 births in younger mothers (<20 years) and 23 per 1,000 births in older mothers (35+ years). The relative risk of all non-chromosomal anomalies for younger mothers (<20 years) was 1.13 (95%CI 1.10-1.17) and 0.97 (95%CI 0.96-0.99) for older mothers (35+ years) compared to the baseline (25-29 years). In 2000-2004 the prevalence for non-chromomsal anomalies in younger mothers was 28 per 1,000 births and 23 per 1,000 in older mothers. Results differed for individual anomalies.

Conclusions
Generall, young maternal age is a stronger risk factor for a wider range of non-chromosomal congenital anomalies than older maternal age. The increasing average age of mothers at childbirth in Europe is not causing an increase in prevalence of non-chromosomal congenital anomalies, as overall risk does not rise with older maternal age. However, teenage mothers are at greater risk of congenital anomalies, and this needs further investigation.

Appendix 10
List of Attendees and Programmes of the 19th, 20th , 21st and 22nd Registry Leaders' Meetings in Bergen, Norway (4-5 June 2004), Poznan, Poland (10-11 June 2005), Graz, Austria (9-10 June 2006) and Naples, Italy (7-9 May 2007)

19th Registry Leaders' Meeting
Bergen, Norway
4-5 June 2004

Addor, Marie-Claude	Switzerland, Vaud
Barisic, Ingeborg	Croatia, Zagreb
Bianchi, Fabrizio	Italy, Tuscany
Borman, Barry	New Zealand
Boyd, Patricia	UK, Oxford
Braz, Paula	Portugal, South
Budd, Judith	UK, Trent
Busby, Araceli	Central Registry
Bythell, Mary	UK, NorCAS
Calzolari, Elisa	Italy, Emilia Romagna
Daltveit, Anne	Norway
De Jong van den Berg, Lolkje	Central Registry
De Vigan, Catherine	France, Paris
De Walle, Hermien	Netherlands, North
Densem, James	Central Registry
Dolk, Helen	Central Registry
Draper, Liz	UK, Trent
Ebner, Arno	Germany, Pomerania
Feijoo, Maria	Portugal, South
Francannet, Christine	France, Auvergne
Garne, Ester	Denmark, Odense
Gasemyr, Kristin	Norway
Gatt, Miriam	Malta
Gillerot, Yves	Belgium, Hainaut
Harris, John	USA
Irgens, Lorentz	Norway
Latos-Bielenska, Anna	Poland
Loane, Maria	Central Registry
Lillis, David	Ireland, Galway
McDonnell, Bob	Ireland, Dublin
Meijer, Willemijn	Netherlands, North
Morris, Joan	UK, NDSCR
Nelen, Vera	Belgium, Antwerp
Norton, Barbara	Central Registry
Queisser-Luft, Annette	Germany, Mainz
Ritvanen, Annukka	Finland
Robert, Elisabeth	France, Central East
Roesch, Christine	Germany, Saxony
Sandor, Janos	Hungary
Soares, Maria	Portugal, South
Steinbicker, Volker	Germany, Saxony
Stoll, Claude	France, Strasbourg
Tenconi, Romano	Italy, North East
Tincheva, Radka	Bulgaria, Sofia

Tokic, Visnja	Croatia, Zagreb
Tucker, David	UK, Wales (CARIS)
Ward-Platt, Martin	UK, NorCAS
Wellesley, Diana	UK, Wessex
Wiesel, Awi	Germany, Mainz

19th Registry Leaders Meeting
Bergen, Norway
4-5 June 2004

Friday 4 June

Thursday evening: reception

08.00 Registration

Session1: 9.00-11.00 News since Heidelberg (Chair: David Lillis)

9.00	Welcome (Lorentz Irgens)
9.05	Apologies and Minutes of Heidelberg Registry Leaders' Meeting
9.10	Project Leaders' Report
9.40	News from New Member Registries and Applicants – Moscow, Northern Region, Pomerania News from Member Registries – North East Italy
10.10	Extending Collaboration with Registries in Eastern Europe (Fabrizio Bianchi)
10.20	The Community's Needs for Perinatal Health Data (Lorentz Irgens)

Session 2: 11.15-13.00 Subgroup meetings I or EDMP Exercises
Coding and Classification Committee
Folic Acid and Neural Tube Defects Working Groups

Session 3: 14.00-16.00 Cluster Investigations and Management (Chair: Elisa Calzolari)
The EUROCAT Surveillance System (Helen Dolk)
The Cluster Advisory Service Website (Araceli Busby)
Using the EDMP to Identify Clusters and Results to 2000 (Maria Loane)
Short Guidelines for Investigating Clusters Detected by Routine Surveillance (Elisabeth Robert)
Presentation of Results of Cluster Investigations and Management (Paris, Tuscany, Dublin, Galway, North Netherlands, Emilia Romagna, Strasbourg, Zagreb, Malta, NE Italy, Antwerp, NW Thames, Wales)
Wales Cluster Detection and Investigation Plans (Dave Tucker)
Schonebeck Chemical Accident Investigations (Christine Roesch)
Congenital Anomalies Near Incinerators (Elisabeth Robert)
Investigation of an Incinerator in Tuscany (Fabrizio Bianchi)

Session 4:	Updates on Ongoing Projects (Chair: Anna Latos-Bielenska) The Finnish Medicines and Pregnancy Project (Annukka Ritvanen) Maternal Age-Specific Prevalence of Non-Chromosomal Anomalies (Maria Loane) Prenatal Diangosis in Europe: Trends and regional Differences (Ester Garne) Down Syndrome Prevalence Among Livebirths: Geographic Inequalities in Europe (Helen Dolk) Trends in Neural Tube Defects in relation to periconceptional Folic Acid Policy (Araceli Busby) Maternal Age-Specific Prevalence of Down Syndrome (Joan Morris) The Effect of Prenatal Diagnosis on Gestational Age at Livebirth (Ester Garne) Results of ICBD Craniofacial Project (Elizabeth Robert) Results of ICBD Gastroschisis Project (Fabrizio Bianchi)
Saturday 5 June	
Session 5:	9.00-11.00 EUROCAT Data (Chair: Catherine de Vigan)
9.00	Presentation of New Guides to Coding of Limb Defects (Ester Garne)
9.10	Guide 1.3 Revision: Final decisions (Ester Garne)
9.50	EDMP: "What it can do for you": An Interactive Session (James Densem, Maria Loane)
10.20	The Results of the EUROCAT Ethics and Consent Survey (Araceli Busby)
Session 6:	11.00-13.00 Subgroup Meetings II or EDMP Exercises Prenatal Diangosis Drugs
Session 7:	14.00-16.00 Proposals for Collaborative Work (Chair: Ingeborg Barisic) Fetopathology: Value and Best practice (Fabrizio Bianchi) Multiple Malformations in EUROCAT Data (Ester Garne) Genetic Counselling: Comparative Situation in Europe (Anna Latos-Bielenska) Down Syndrome Risk in Siblings (Joan Morris) Assisted Conception and rare Syndromes (Annette Queisser-Luft) Assisted Conception and Congenital Anomalies (Catherine de Vigan) Prevalence of Selected Syndromes in EUrocat (Ingeborg Barisic) Risk Factors for Heart Defects in Down Syndrome (Anna Latos-Bielenska) Sex Ratio of Malformations (Ester Garne) *Other proposals from EUROCAT Members*
Session 8:	16.30-18.00 Closing Session (Chair: David Lillis)
16.30	Next RLM 2005 (+ Symposium) 2006
16.45	EUROCAT Association Meeting

20th Registry Leaders' Meeting
Poznan, Poland
10-11 June 2005

Abramsky, Lenore	UK, North Thames
Bakker, Mariam	Netherlands, North
Balode, Ieva	Latvia
Barisic, Ingeborg	Croatia, Zagreb
Bianchi, Fabrizio	Italy, Tuscany
Boyd, Tricia	UK, Oxford
Braz, Paula	Portugal, South
Budd, Judith	UK, Trent
Busby, Araceli	Central Registry
Calzolari, Elisa	Italy, Emilia Romagna
Chapple, Jean	UK, North Thames
Costigan, Johanna	Ireland, Dublin
Cotter, Benvon	Ireland, Cork & Kerry
Daltveit, Anne	Norway
De Jong van den Berg, Lolkje	Central Registry
De Vigan, Catherine	France, Paris
De Walle, Hermien	Netherlands, North
Densem, James	Central Registry
Dolk, Helen	Central Registry
Draper, Elizabeth	UK, Trent
Ebner, Arno	Germany, Pomerania
Fedoryshyn, Zorvana	Ukraine
Garne, Ester	Denmark, Odense
Gatt, Miriam	Malta
Gillerot, Yves	Belgium, Hainaut-Namur
Gorina, Olga	Ukraine
Hand, Elaine	Central Registry
Hoyer-Schuschke, Jana	Germany, Saxony-Anhalt
Khoshnood, Babak	France, Paris
Latos-Bielenska	Poland
Lillis, David	Ireland, Galway
Lisi Alessandra	Italy, ICBD
Loane, Maria	Central Registry
Lynchak, Oksana	Ukraine
Mastrioacovo, Pierpaolo	Italy, ICBD
Materna-Kiryluk, Anna	Poland
Mejnartowicz, Jan	Poland
Mols, Myriam	Belgium, Hainaut-Namur
Morris, Joan	UK, E&W Down Syndrome
Nelen, Vera	Belgium, Antwerp
Norton, Barbara	Central Registry
Pierini, Anna	Italy, Tuscany
Portillo, Isabel	Spain, Basque Country
Poetzsch, Simone	Germany, Saxony-Anhalt
Queisser-Luft, Annette	Germany, Mainz
Ritvanen, Annukka	Finland
Rounding, Catherine	UK, Oxford
Scarano, Gioacchino	Italy, Campania
Steinbicker, Volker	Germany, Saxony-Anhalt

Stoll, Claude	France, Strasbourg
Tenconi, Romano	Italy, North East
Tucker, Dave	UK, Wales
Veazey, Hannah	UK, North Thames
Wellesley, Diana	UK, Wessex
Wiesel, Awi	Germany, Mainz
Williamson-North, Hayley	UK, North Thames
Zatsepin, Ivan	Belarus
Zhuchenko, Ludmila	Russia

20th Registry Leaders' Meeting
Poznan, Poland
11 June 2005

Morning: Chair – Liz Draper and Hermien de Walle

09.00 Welcome (Anna Latos-Bielenska)

09.05 Apologies and Minutes (David Lillis)

09.10 Project Leader's Guide to the Meeting (Helen Dolk)

09.20 In Memory of Christine Roesch (Simone Poetzsch)

09.35 News from Registries and Applicant Members:

Belarus	Moscow	Basque Country
Latvia	Ukraine	Poland-web Registration

10.10 Developments at EUROCAT Central Registry for Discussion:

- Launch of the new EDMP: What it can do for you (James Densem)
- Perinatal and infant Survival (Elaine Hand)
- Data Quality Indicators (Maria Loane and Ester Garne)
- Implementation of Guide 1.3 – A quick reminder (Ester Garne)
- Monitoring of Multiple Malformations (Ester Garne)
- Aetiological Coding Scheme (Diana Wellesley)
- Survey of Registry Resources (Isobel Portillo)

12.00 Subgroup Session 1:

- Coding and Classification (members only) **OR** NTD and Folic Acid **OR** Fetopathology **OR** EDMP Exercises

Afternoon: Chair – Vera Nelen and Tricia Boyd

14.00 Statistical Surveillance to 2002 and Beyond:

- Introduction (Araceli Busby and Helen Dolk)
- Use of EDMP for Local Surveillance (Araceli Busby)
- Results of Investigations of Clusters and Trends (All Registries)

15.45 Collaborative Projects:

- Writing a Project Proposal (Helen Dolk)
- Prevalence of Syndromes (Helen Dolk and Ingeborg Barisic)
- Hypospadias and Loratidine: What we can learn from this case-control study (Lolkje de Jong van den Berg)
- Down Syndrome: Recurrence Risk and the Paternal Age-Related Risk of Chromosome Anoamlies (Joan Morris)
- Gastroschisis Case-Control Study (Fabrizio Bianchi)
- The FOCAL Project (Diana Wellesley)

16.45	Subgroup Session 2: Prenatal Diagnosis **OR** Drugs **OR** EDMP Exercises **OR** Hospital Activity Data **OR** Genetic Services
17.45	Reports from: ICBDMS/ICBD (Pierpaolo Mastrioacovo) RDTF (Helen Dolk)
18.00	EUROCAT Association Meeting

21st Registry Leaders' Meeting
Graz, Austria
9-10 June 2006

Bakker, Marian	Netherlands, North
Baloda, Ieva	Latvia
Barisic, Ingeborg	Croatia, Zagreb
Berghold, Andrea	Austria, Styria
Bianca, Sebastiano	Italy, Sicily (ISMAC)
Bianchi, Fabrizio	Italy, Tuscany
Boyd, Patricia	UK, Oxford
Budd, Judith	UK, Trent
Calzolari, Elisa	Italy, Emilia Romagna
Costigan, Johanna	Ireland, South East
Daltveit, Anna	Norway
De Jong-van den Berg, Lolkje	Central Registry
Densem, James	Central Registry
De Vigan, Catherine	France, Paris
De Walle, Hermien	Netherlands, North
Dolk, Helen	Central Registry
Doray, Berenice	France, Strasbourg
Draper, Liz	UK, Trent
Ebner, Arno	Germany, Pomerian
Garne, Ester	Denmark, Odense
Gatt, Miriam	Malta
Gillerot, Yves	Belgium, Hainaut-Namur
Gray, Ron	Invited Speaker
Guerts, Marlies	Netherlands, North
Haeusler, Martin	Austria, Styria
Hong, Suzhuang	Central Registry
Khoshnood, Babak	France, Paris
Latos-Bielenska, Anna	Poland
Lillis, David	Ireland, Galway
Loane, Maria	Central Registry
Mastrioacovo, Pierpaolo	Italy, ICBDSR
Materna-Kiryluk, Anna	Poland
McDonnell, Bob	Ireland, Dublin
Mejnartowicz, Jan	Poland
Mirtskhulava, Merab	Georgia, Tbilisi
Mols, Myriam	Belgium, Hainaut-Namur
Morris, Joan	UK, NDSCR
Nelen, Vera	Belgium, Antwerp
Norton, Barbara	Central Registry
O'Driscoll, Christine	Ireland, Cork & Kerry
Pelkic, Ksenija	Slovenia
Perthus, Isabelle	France, Auvergne
Pierini, Anna	Italy, Tuscany
Poetzsch, Simone	Germany, Saxony-Anhalt
Portillo, Isabel	Spain, Basque Country
Queisser-Luft, Annette	Germany, Mainz
Ritvanen, Annukka	Finland
Rounding, Catherine	UK, Oxford
Scarano, Gioacchino	Italy, Campania

Tenconi, Romano	Italy, North East
Tucker, David	UK, Wales (CARIS)
Wellesley, Diana	UK, Wessex
Wertelecki, Wladimir	Ukraine, OMNI-NET
Wiesel, Awi	Germany, Mainz
Zymak-Zakutnia, Natalia	Ukraine, OMNI-NET

21st Registry Leaders' Meeting
Graz, Austria
9-10 June 2006

Friday 9 June

Session 1:	08.30-10.00 News Since Poznan (Chair: Martin Haeusler)
08.30	Welcome (Martin Haeusler)
08.35	Apologies and Minutes of Poznan Registry Leaders' Meeting
08.40	Project Leaders' Report (Helen Dolk)
09.10	News from New Member, Applicant Registries and new Registry Leaders (Slovenia, South East Ireland, Latvia, Georgia, Strasbourg)
09.40	Guide 1.3 EDMP: Important New Developments (James Densem, Maria Loane)
Session 2:	10.40-12.00 Central Registry Developments (Chair: Miriam Gatt)
	Data Quality Indicators (Maria Loane)
	Malformation Coding and New Subgroups (Ester Garne)
	Multiple Malformation Surveillance (Ester Garne)
	Future Issues in Surveillance (Helen Dolk)
	EUROCAT 2007-2010 (Helen Dolk)
Session 3:	12.00-13.00 Parallel Sessions I
	Hospital Activity Data (Dave Tucker, Helen Dolk)
	EDMP Clinic (James Densem, Maria Loane)
	Induction Session for New Registries (Fabrizio Binachi)
Session 4:	14.00-16.00 Statistical Surveillance and Cluster Investigations (Chair: Andrea Berghold)
	Statistical Surveillance Strategy (Helen Dolk)
	Changes made to EDP Statistical Surveillance and Demonstration (Maria Loane, James Densem)
	Clusters Detected by Routine Surveillance (Maria Loane)
	Presentations and Discussion of Results of Cluster Investigations and Management (18 EUROCAT Registries – Hainaut, Odense, Paris, Tuscany, Dublin, Emilia Romagna, S Portugal, Basque Country, Saxony-Anhalt, Barcelona, North Thames, Cork & Kerry, ISMAC, Campania, CARIS, Wielkopolska, NorCAS, Hungary)

Saturday 10 June

Session 5:	08.30-09.30 Foetal Alcohol Syndrome (Chair: Liz Draper)
08.30	Invited Speaker: Dr Ron Gray, National Perinatal Epidemiology Unit
09.00	The Finnish Situation (Annukka Ritvanen)
09.05	Discussion
Session 6:	09.20-10.50 Drugs Workshop – Plenary Session (Chair: Lolkje de Jong van den Berg)
	Use of ATC Coding: Experience and Guidelines (Lolkje de Jong v d Berg)
	Analysis of EUROCAT Data on Drugs (Lolkje de Jong v d Berg)
	Future Plans and Workpackage 2007-2010
Session 7:	11.20-12.15 Parallel Session II
	Drugs (Lolkje de Jong van den berg)
	EDMP Clinic (James Densem, Maira Loane)
	Coding & Classification Committee (Members Only, Ester Garne, Ingeborg Barisic)
Session 8:	12.15-13.00 Reports from Working Groups and Research Projects (Chair: Ingeborg Barisic)
	Prenatal Diagnosis
	Prenatal Screening Policies (Patricia Boyd)
	TGA (Ester Garne)
	Workpackage 2007-2010
	Folic Acid
	General Report (Hermien de Walle)
	Workpackage 2007-2010
	Chernobyl and Neural Tube Defects in the Ukraine (Wladimir Wertelecki)
	Genetic Syndromes and Family History
	Genetic Counselling Services in Europe (Isabel Portillo, Inbegorg Barisic)
	Cornelia de Lange Syndrome and Other rare Diseases (Ingeborg Barisic)
	Sentinel Phenotypes (Suzhuang Hong, Helen Dolk)
	Multiple Malformations: Malformation in Relatives (Elisa Calzolari)
	Down Syndrome
	Recurrence (Joan Morris)
	Paternal Age (Joan Morris)
	Trends in Prevalence (Maria Loane, Helen Dolk)
	Maternal Disease
	AMC (Anne Daltveit)
	Diabetes (Ester Garne, Lolkje de Jong van den Berg)
	Gastroschisis Case-Control Study (Fabrizio Bianchi)
	Project Proposals
Session 9:	16.10-17.30 Closing Session (Chair: David Lillis)
16.10	ICBDSR (Pierpaola Mastriacovo)
16.15	EUROCAT Budget (Helen Dolk)
16.30	Next RLM 2007 (+ Symposium (Gioacchino Scarano)
16.35	RLM 2008 (Annukka Ritvanen)
16.40	Closing Comments (David Lillis)

22nd Registry Leaders' Meeting
Naples, Italy
7-9 May 2007

Addor, Marie-Claude	Switzerland, Vaud
Alessandri, Jean Luc	France, Ile de la Reunion
Amar, Emmanuelle	France, Central East
Ayme, Segolene	Invited Speaker
Bakker, Marian	Netherlands, North
Balode, Ieva	Latvia
Barisic, Ingeborg	Croatia , Zagreb
Bianca, Sebastiano	Italy, Sicily (ISMAC)
Bianchi, Fabrizio	Italy, Tuscany
Boyd, Tricia	UK, Oxford
Braz, Paula	Portugal, South
Budd, Judith	UK, Trent
Bythell, Mary	UK, NorCAS
Calzolari, Elisa	Italy, Emilia Romagna
Densem, James	Central Registry
De Jong van den Berg, Lolkje	Central Registry
De Vigan, Catherine	France, Paris
De Walle, Hermien	Netherlands, North
De Wals, Phillippe	Invited Speaker
Dias, Carlos	Portugal, South
Dolk, Helen	Central Registry
Doray, Berenice	France, Strasbourg
Draper, Liz	UK, Trent
Ebner, Arno	Germany, Pomerania
Garne, Ester	Denmark, Odense
Gatt, Miriam	Malta
Gillerot, Yves	Belgium, Hainaut
Greenlees, Ruth	Central Registry
Haeusler, Martin	Austria , Styria
Irgens, Lorentz	Norway
Jentink, Janneke	Central Registry
Klungsoyr, Kari	Norway
Latos-Bielenska, Anna	Poland
Lillis, David	Ireland, Galway
Lindhout, Dick	Invited Speaker
Loane, Maria	Central Registry
Lowry, Brian	Invited Speaker
Materna-Kiryluk, Anna	Poland
Mejnartowicz, Jan	Poland
Mols, Myriam	Belgium, Hainaut
Morris, Joan	UK, NDSCR
Nelen, Vera	Belgium, Antwerp
Neville, Amanda	Italy, Emilia Romagna
Norton, Barbara	Central Registry
O'Mahony, Mary	Ireland, Cork & Kerry
Pierini, Anna	Italy, Tuscany
Portillo, Isabel	Spain, Basque Country
Queisser-Luft, Annette	Germany, Mainz
Rankin, Judith	UK, NorCAS

Ritvanen, Annette	Finland
Rivieri, Francesca	Italy, Emilia Romagna
Roch, Beth-Ann	Ireland, South East
Rounding, Catherine	UK, Oxford
Ruddock, Vera	UK, NCAS
Scarano, Gioacchino	Italy, Campania
Thys, Guy	Belgium, Antwerp
Tokic, Visnja	Croatia , Zagreb
Tucker, Dave	UK, Wales (CARIS)
Wellesley, Diana	UK, Wessex
Wiesel, Awi	Germany, Mainz

22nd Registry Leaders' Meeting
Naples, Italy
7-9 May 2007

Tuesday 8 May 2007

09.00-10.15	**Session 1:**	**(Chair: Catherine de Vigan)**
09.00-09.05	Welcome (Gioacchino Scarano)	
09.05-09.10	Apologies and Approval of Minutes of Last Meeting (Chair)	
09.10–09.20	Introduction Global Report on Health Status in Europe: Chapter on Congenital Anomalies (Helen Dolk)	
09.20-09.25	The next EUROCAT Contract 2007-2010 (Helen Dolk)	
09.25-09.30	Congenital Anomaly Surveillance in Campania (Gioacchino Scarano)	
09.30-09.40	Congenital Anomaly Surveillance in Canada (Brian Lowry)	
09.40-09.45	News from New and Applicant Member Registries: Ile de la Reunion	
09.45-10.05	News from Member Registries (Poland, Central East France, South Portugal, England & Wales NCAS)	
10.05-10.10	EUROCAT Association (Catherine de Vigan)	
10.10-10.25	A Historical View: In Memoriam of Josephine Weatherall (David Lillis)	
11.00-12.00	**Session 2:**	**Drugs (Chair: Hermien de Walle)**
11.00-11.40	The EURAP Study (Dick Lindhout)	
11.40-11.50	The EUROCAT Lamotrigine Study (Lolkje de Jong van den Berg)	
11.50-12.00	The Finland Epilepsy Study (Annukka Ritvanen)	
12.00-13.00	**Session 3:**	**Data Quality (Chair: Tricia Boyd)**
12.00-12.30	Evaluation of New Guide 1.3 Coding (Ester Garne)	
12.30-12.45	DQI Trends (Maria Loane)	
12.45-13.00	EDMP Changes (James Densem)	
14.00-16.00	Lamotrigine Study Working Meeting (study participants only)	

Wednesday 9 May 2007

09.00-11.00	**Session 4:**	**Malformation and Syndrome Coding Workshop (Ingeborg Barisic, Diana Wellesley and Ester Garne)**
09.00-09.10	Introduction to Coding (Ester Garne)	
09.10-09.25	Translating Karyotypes to ICD10-BPA (Diana Wellesley)	
09.25-09.40	Guide 6 and McKusick/OMIM Coding (Ingeborg Barisic)	
09.40-09.50	Rare Diseases Task Force Coding Working Group Developments (Segolene Ayme)	
09.50-10.15	ICD10 Updates, Microdeletions, Maternal Infections and Teratogenic Exposures, Minor Malformations, Important BPA Extensions, Coding Tips – Where to Find Them, Results of the Multiple Malformations Study and Coding Implications (Ester Garne)	
10.15-10.45	Small Group exercises for all Participants using ICD/BPA10	
10.45-11.00	Discussion of Exercises	
11.30-13.00	**Session 5:**	**(Chair: Anna Latos-Bielenska)**
11.30-12.30	Report from Budapest Meeting (Helen Dolk) Statistical Monitoring for 2005 Overview (Maria Loane), Switzerland (Marie-Claude Addor), Hainaut (Yves Gillerot), Paris (Catherine de Vigan), Tuscany (Fabrizio Bianchi), N Netherlands (Marian Bakker), Antwerp (Vera Nelen), Saxony (Simone Poetzsch), CARIS (Dave Tucker), Norway (Lorentz Irgens), Wessex (Diana Wellesley), NorCAS (Judith Rankin/Mary Bythell)	
12.30-13.00	Working Group Meetings: Foetal Alcohol Syndrome Working Group (Liz Draper) Hospital Activity Data (Dave Tucker) Guide 1.3 Coding Issues Group (Ester Garne, Maria Loane) Fetal Pathology Group (Fabrizio Bianchi) EDMP Clinic (James Densem, Maria Loane)	
14.00-18.00	**Session 6:**	**(Chair: Elisa Calzolari)**
14.00-15.00	Working Group Meetings: Folic Acid Working Group Meeting (Hermien de Walle) Coding Workshop (members only) (Ester Garne) EDMP Clinic (James Densem, Maria Loane)	
15.00-16.00	Working Group Meetings: Drugs Working Group (lolkje de Jong van den Berg) EDMP Clinic (James Densem, Maria Loane) Prenatal Diagnosis Working Group (Ester Garne)	
16.00-16.30	Feedback from Working Group Meetings Foetal Alcohol Syndrome Working Group (Liz Draper) Hospital Activity Data (Dave Tucker) Guide 1.3 Coding Issues Group (Ester Garne) Fetal Pathology Group (Fabrizio Bianchi) Folic Acid Working Group (Hermien de Walle)	

	Coding Committee (Ester Garne)
	Drugs Working Group (Lolkje de Jong van den Berg)
	Prenatal Diagnosis Working Group (Ester Garne)
16.30-17.05	EUROCAT Association Meeting
17.05-17.50	Study progress Reports and project proposals
	AMC (Lorentz Irgens)
	Down Syndrome: Paternal Age, Recurrence Risk (Joan Morris)
	Cornelia de Lange (Ingeborg Barisic)
	Hydrocephaly (Ester Garne)
	Renal (Ester Garne)
	New proposals
	Research Funding Sources, FP7 (Helen Dolk)
17.50-18.00	Next Meetings
	Close of Meeting

Appendix 11
Programme and Abstracts from the 8th and 9th European Symposiums "Prevention of Congenital Anomalies"

www.eurocat.ulster.ac.uk/pubdata/Poznan-2005.html

www.eurocat.ulster.ac.uk/pubdata/Naples-2007.html

Appendix 12
Methodological Approaches to the Assessment of Risk of Congenital Anomaly due to Environment Pollution, Budapest Workshop, 6-7 March 2007-12-18

www.eurocat.ulster.ac.uk/Environment-Pollution.html