Eurocat

European Surveillance of Congenital Anomalies

WHO COLLABORATING CENTRE FOR THE EPIDEMIOLOGIC SURVEILLANCE OF CONGENITAL ANOMALIES

REPORT 2004-2005

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Terms of reference:

1. To provide essential epidemiologic information on congenital anomalies in Europe
2. To facilitate the early warning of teratogenic exposures and act as an information and resource centre regarding clusters or exposures or risk factors of concern
3. To evaluate the effectiveness of primary prevention and assess the impact of developments in prenatal screening
4. To promote the exchange of experience on population-based registration methods, classification and coding of congenital anomalies, and surveillance methods.

Terms of reference 1:
To provide essential epidemiologic information on congenital anomalies in Europe

EUROCAT currently has 40 members in 20 countries (see Table 1), including new members South East Ireland and Ukraine. Of these, 34 are full members transmitting individual level data on congenital anomalies and 6 are associate members transmitting only yearly aggregate numbers. In total, almost 1.5 million births per year are surveyed, covering 29% of the births in EU member states and 19% of births in four non-EU countries. The central database holds a total of 375,000 cases of congenital anomaly since 1980 including livebirths, stillbirths and terminations of pregnancy following prenatal diagnosis. In 2005, the definition of subgroups was revised (EUROCAT 2005, "EUROCAT Guide 1.3: Instruction for the Registration of Congenital Anomalies", *EUROCAT Central Registry*, University of Ulster). The first set of prevalence data for the new subgroups was produced. Average total prevalence rates for 92 congenital anomaly subgroups 2000-2004 are given in Table 2.

The EUROCAT Website, under Publications and Data (www.eurocat.ulster.ac.uk/pubdata/tables.html), gives open access to prevalence data on subgroups of congenital anomalies, with user choice regarding congenital anomaly(s) of interest, years of interest, and registries or countries of interest in order to produce a range of table formats that can be readily printed. Prevalence rates are given as livebirth prevalence rates, birth prevalence rates, and total prevalence rates (the latter including also terminations of pregnancy following prenatal diagnosis). Prevalence data were updated to the birth year 2004.

In 2003, EUROCAT began to provide the WHO International Database on Craniofacial Anomalies with data on cleft lip and cleft palate from European countries, and this has continued annually. The results appear on the WHO Genomic Resource Centre website http://www.who.int/genomics/anomalies/idcfa/en/.

The latest EUROCAT publications on facial clefts are:

> Calzolari E, Pierini A, Astolfi G, Bianchi F, Neville A, Riveri F and a EUROCAT Working Group (in press), "Associated Anomalies in Multi-Malformed Infants with Cleft Lip and Palate: An Epidemiological Study Based on Nearly 6 Million Births in 23 EUROCAT Registries", *American Journal of Medical Genetics.*
>
> 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.

Work has proceeded to produce prevalence data on a list of approximately 20 rare congenital syndromes which have not previously been extracted from the EUROCAT database. The results concerning Cornelia de Lange syndrome are ready for publication. Work is ongoing on Apert syndrome and some of the skeletal dysplasias, with a special emphasis on monitoring of new mutations. Work has also been ongoing on the epidemiology of multiple malformations, particularly the validation of a computer algorithm for identifying “potential multiples” for further review by

medical geneticists, preparatory to routine surveillance of multiple malformations. A first report of this work is in preparation.

In 2004, EUROCAT contributed data on congenital anomalies for the WHO European Health Report 2005.

EUROCAT is working with the Rare Diseases Task Force of the European Union (www.rdtf.org) to improve information on rare diseases, including congenital anomalies, in Europe.

For general information on EUROCAT, see 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.

Table 1. Coverage of the European Population by EUROCAT Registries

Country	Registry	Annual Births Registry	Annual Births Country	% Country Covered
EU Countries				
Austria	Styria	10,500	82,000	12.8
Belgium	Antwerp	18,100		
	Hainaut	12,000		
	Total	30,100	115,500	26.1
Cyprus			8,100	0.0
Czech Republic			10,200	0.0
Denmark	Odense	5,300	64,800	8.1
Finland	*	56,800	56,800	100.0
France	Auvergne	13,400		
	Paris	38,300		
	Central East*	91,000		
	Strasbourg	13,400		
	Total	156,100	789,100	19.8
Germany	Mainz	3,200		
	Saxony-Anhalt	17,000		
	Total	20,100	742,500	2.7
Greece	Total	0	99,900	0.0
Hungary		113,800	113,800	100.0
Ireland	Cork & Kerry	8,500		
	Dublin	23,400		
	SE Ireland	6,300		
	Total	38,200	65,600	58.2
Italy	Campania	59,900		
	Emilia Romagna	27,400		
	North East	60,200		
	Sicily	16,000		
	Tuscany	27,700		
	Total	191,300	528,300	36.2
Latvia		0	20,700	0.0
Lithuania		0	30,600	0.0
Luxembourg		0	6,000	0.0
Malta		3,900	3,900	100.0
Netherlands	North	20,000	195,600	10.2
Poland	Wielkopolska	33,600		
	Rest of Poland*	217,900		
	Total	251,500	343,800	73.2
Portugal	South	18,100	116,600	15.5
Slovakia		0	54,000	0.0
Slovenia		0	18,000	0.0
Spain	Asturias	7,200		
	Barcelona	14,300		
	Basque Country	19,300		
	Madrid (ECEMC)*	103,100		
	Total	144,000	478,500	30.1
Sweden	*	99,500	99,500	100.0
UK	Northern Region	30,300		
	North Thames	48,500		
	Oxford	6,700		

	Trent	64,300		
	Wales (CARIS)	31,300		
	Wessex	26,300		
	Total	207,400	721,200	28.8
TOTAL		**1,366,700**	**4,778,000**	**28.6**
Non-EU Countries				
Croatia	Zagreb	5,500	39,600	13.8
Norway	*	57,400	57,400	100.0
Switzerland	Vaud	6,900	74,000	9.3
Ukraine		42,400	423,900	10.0
TOTAL		**112,100**	**594,900**	**18.8**
GRAND TOTAL		**1,478,800**	**5,373,000**	**27.5**

*Associate members

Table 2. Number of cases among livebirths, stillbirths and terminations of pregnancy following prenatal diagnosis, and prevalence per 10,000 births, of 92 congenital anomaly subgroups in 32 EUROCAT full member registries, 2000-2004. Prevalence of non-chromosomal subgroups also shows rates excluding chromosomal anomalies.

Registries = Hainaut (B), Odense (DK), Paris (F), Tuscany (I), Dublin (IRL), N Netherlands (NL), Emilia Romagna (I), Strasbourg (F), Switzerland, Zagreb (HR), Malta (M), North East Italy (I),S Portugal (P), Antwerpen (B), Basque Country (E), Asturias (SP), Saxony Anhalt (D), Mainz (D), Barcelona (SP), Styria (AU), North Thames (UK), ISMAC (I), Campania (I), Wales (UK), Auvergne (F), Wielkopolska (PL), Oxford (UK), Wessex, Trent (UK), NorCAS (UK), Hungary, SE Ireland (IRL). Total births 200-2004: 3477335

						Excluding Chromosomal	
Anomaly Subgroup	LB (n)	FD (n)	TOP (n)	LB+FD+TOP (n)	LB+FD+TOP (rate)	LB+FD+TOP (n)	LB+FD+TOP (rate)
All Anomalies	60940	1507	13676	76123	218.91	64412	185.23
Nervous system	3385	330	4053	7768	22.34	6999	20.13
Neural Tube Defects	889	157	2277	3323	9.56	3177	9.14
Anencephalus and similar	129	93	1055	1277	3.67	1248	3.59
Encephalocele	108	17	241	366	1.05	352	1.01
Spina Bifida	652	47	981	1680	4.83	1577	4.54
Hydrocephaly	860	94	891	1845	5.31	1663	4.78
Microcephaly	581	22	85	688	1.98	615	1.77
Arhinencephaly/holoprosencephaly	101	18	359	478	1.37	294	0.85
Eye	1105	17	95	1217	3.5	1077	3.1
Anophthalmos/micropthalmos	254	11	65	330	0.95	270	0.78
Anophthalmos	53	5	15	73	0.21	64	0.18
Congenital cataract	300	1	3	304	0.87	284	0.82
Congenital glaucoma	72	1	0	73	0.21	71	0.2
Ear, face and neck	715	25	215	955	2.75	786	2.26
Anotia	95	1	8	104	0.3	101	0.29
Congenital heart disease	20985	367	2278	23630	67.95	20738	59.64
Common arterial truncus	215	9	70	294	0.85	246	0.71
Transposition of great vessels	944	12	85	1041	2.99	1012	2.91
Single ventricle	120	9	72	201	0.58	188	0.54
Ventricular septal defect	8950	107	665	9722	27.96	8686	24.98
Atrial septal defect	6735	59	198	6992	20.11	6239	17.94

Atrioventricular septal defect	804	37	342	1183	3.4	500	1.44
Tetralogy of Fallot	910	27	123	1060	3.05	905	2.6
Tricuspid atresia and stenosis	184	4	71	259	0.74	247	0.71
Ebstein's anomaly	102	8	18	128	0.37	117	0.34
Pulmonary valve stenosis	1079	7	36	1122	3.23	1076	3.09
Pulmonary valve atresia	208	9	67	284	0.82	263	0.76
Aortic valve atresia/stenosis §	328	4	41	373	1.07	354	1.02
Hypoplastic left heart	435	29	392	856	2.46	776	2.23
Hypoplastic right heart §	58	7	44	109	0.31	101	0.29
Coarctation of aorta	1092	19	81	1192	3.43	1068	3.07
Total anomalous pulm venous return	144	1	12	157	0.45	152	0.44
Respiratory	1165	144	542	1851	5.32	1620	4.66
Choanal atresia	273	2	10	285	0.82	277	0.8
Cystic adenomatous malf of lung §	98	1	23	122	0.35	120	0.35
Oro-facial clefts	4236	96	539	4871	14.01	4458	12.82
Cleft lip with or without palate	2535	58	380	2973	8.55	2708	7.79
Cleft palate	1701	38	159	1898	5.46	1750	5.03
Digestive system	3898	153	684	4735	13.62	4218	12.13
Oesophageal atresia with or without tracheo-oesophagal fistula	657	14	83	754	2.17	693	1.99
Duodenal atresia or stenosis	313	22	35	370	1.06	265	0.76
Atresia or stenosis of other parts of small intestine	186	7	5	198	0.57	192	0.55
Ano-rectal atresia and stenosis	767	29	217	1013	2.91	945	2.72
Hirchspung's disease	299	0	3	302	0.87	264	0.76
Atresia of bile ducts	90	1	5	96	0.28	93	0.27
Annular pancreas	39	0	10	49	0.14	33	0.09
Diaphragmatic hernia	692	39	180	911	2.62	818	2.35
Abdomnal wall defects	1089	100	673	1862	5.35	1580	4.54
Gastroschisis	626	28	109	763	2.19	750	2.16
Omphalocele	440	67	507	1014	2.92	752	2.16
Urinary	8231	225	1606	10062	28.94	9517	27.37
Bilateral renal agenesis including Potter syndrome	106	40	277	423	1.22	408	1.17
Cystic kidney disease	1355	46	457	1858	5.34	1766	5.08

Congenital hydronephrosis	2981	26	222	3229	9.29	3099	8.91
Bladder extrophy and/or epispadia	133	3	29	165	0.47	162	0.47
Posterior urethral valve and/or prune belly	150	1	74	225	0.65	219	0.63
Genital	5042	49	250	5341	15.36	5173	14.88
Hypospadias	4118	7	38	4163	11.97	4098	11.78
Indeterminate sex	194	13	46	253	0.73	235	0.68
Limb	9913	249	1388	11550	33.22	10757	30.93
Limb reduction	1393	90	526	2009	5.78	1847	5.31
Upper limb reduction	965	65	323	1353	3.89	1250	3.59
Lower limb reduction	408	31	219	658	1.89	617	1.77
Complete absence of a limb	9	5	31	45	0.13	44	0.13
Club foot - talipes equinovarus	2149	70	293	2512	7.22	2391	6.88
Hip dislocation and/or dysplasia	1820	2	4	1826	5.25	1813	5.21
Polydactyly	2499	28	227	2754	7.92	2537	7.3
Syndactyly	1672	29	155	1856	5.34	1704	4.9
Arthrogryposis multiplex congenita	113	11	87	211	0.61	197	0.57
Musculo-skeletal	1782	118	886	2786	8.01	2546	7.32
Thanatophoric dwarfism	31	5	69	105	0.3	103	0.3
Jeunes syndrome	16	0	32	48	0.14	48	0.14
Achondroplasia	108	0	27	135	0.39	132	0.38
Craniosynostosis	353	8	26	387	1.11	354	1.02
Congenital constriction bands/amniotic band	44	15	38	97	0.28	97	0.28
Other malformations	2515	105	626	3246	9.33	2986	8.59
Asplenia	18	1	17	36	0.1	33	0.09
Situs inversus	151	3	51	205	0.59	197	0.57
Conjoined twins	10	5	51	66	0.19	66	0.19
Disorders of skin	1208	16	129	1353	3.89	1229	3.53
Teratogenic syndromes with malformations §	138	13	60	211	0.61	200	0.58
Maternal infections resulting in malformations	57	9	47	113	0.32	113	0.32
Genetic syndromes + microdeletions	1239	52	310	1601	4.6	1525	4.39
Chromosomal	4821	429	6461	11711	33.68	0	0
Down Syndrome	3087	130	3471	6688	19.23	0	0

Patau syndrome/trisomy 13	132	29	433	594	1.71	0	0
Edward syndrome/trisomy 18	285	118	1046	1449	4.17	0	0
Turner's syndrome	194	56	516	766	2.2	0	0
Klinefelters syndrome	173	5	150	328	0.94	0	0
Cru-du-chat syndrome	32	1	7	40	0.12	0	0
Wolff-Hirschorn syndrome	32	1	17	50	0.14	0	0

LB=Livebirths
FD= Fetal deaths/stillbirths from 20 weeks gestation
TOP= Terminations following prenatal diagnosis

Terms of reference 2:
To facilitate the early warning of teratogenic exposures and act as an information and resource centre regarding clusters or exposures or risk factors of concern

In 2004, the EUROCAT Cluster Advisory Service was launched as an active part of the website (www.eurocat.ulster.ac.uk/clusteradservice.html). The service consists of the following sections:

HOW UNUSUAL IS AN OBSERVED CLUSTER OF ANOMALIES?
CLUSTER INVESTIGATION PROTOCOLS
RISK PERCEPTION AND RISK COMMUNICATION
A REVIEW OF ENVIRONMENTAL RISK FACTORS FOR CONGENITAL ANOMALIES
COMPLETED CLUSTER INVESTIGATIONS: A DATABASE OF REFERENCES

A literature review of the scientific evidence regarding environmental exposures, including lifestyle exposures and pollution, accompanied the launch of the CAS:

EUROCAT (2004) EUROCAT Special Report: A Review of Environmental Risk Factors for Congenital Anomalies. *EUROCAT Central Registry*, University of Ulster, ISBN 1-85923-187-X.

The aim of general statistical monitoring over time is to identify increases or clusters that may be due to changing exposure to teratogens in the environment. In practice, statistical monitoring also operates as a data quality monitoring system. Statistical monitoring based on the Scan method has been developed for use by Central Registry and local registries. The software has been integrated into the EUROCAT Data Management Programme for central and local use. In 2004 and 2005, analysis of trends and clusters was conducted by EUROCAT Central Registry and discussed at the Registry Leaders Meetings. The first report of results will be available in October 2006.

A Working Group on Drugs during Pregnancy, chaired by Prof Lolkje van den Berg (Netherlands) have advised on the introduction of international ATC coding for drug exposures which has been implemented for births from 2005. This coding system is maintained by the WHO Working Group on ATC coding ((http://www.whocc.no/atcdd). A summary of information in the EUROCAT database relating to drug exposures has also been made, including methods of data collection and numbers of cases by drug category. Twenty registries collected data on drug exposure in the first trimester of pregnancy, with the main source of information being obstetric records. For the 5 years from 1996-2000, nearly two thousand cases were recorded in the EUROCAT database of at least one drug exposure by 14 registries using the 18-category EUROCAT drug code, 12% of all cases in these registers. Additional registries were already using ATC coding. Despite the difficulties of collecting complete information on drugs, the database represents a considerable resource for further investigations.

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

Observations in many countries worldwide of a rise in the prevalence of gastroschisis, a high relative risk among young mothers, and an association with socioeconomic deprivation, have led to concern regarding its future prevention. A EUROCAT analysis of trends was undertaken, confirming the high rate in young mothers and increase in prevalence in Europe 1980-2002, and showing that the increase in prevalence occurred across maternal ages, not just in the youngest high risk group, and revealing a lack of increase in prevalence in Italy. Results will be published in 2006.

Other publications relating to teratogenic exposures and clusters in 2004-2005 were as follows:

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.

Busby A, Armstrong B, Dolk H (2005), "Eye Anomalies: Seasonal Variation and Maternal Viral Infections", *Epidemiology*, Vol 16, No 3, pp 317-322.

Terms of reference 3:
To evaluate the effectiveness of primary prevention and assess the impact of developments in prenatal screening

Prevention of neural tube defects by folic acid supplementation

Approximately 4500 pregnancies every year in the European Union result in a livebirth, stillbirth or termination of pregnancy of a baby/fetus affected by Neural Tube Defects (NTD), mainly anencephaly and spina bifida. Periconceptional folic acid supplementation has been shown over a decade ago to be an effective method of preventing potentially two thirds of cases. A study was conducted by the EUROCAT Working Group on NTD and Folic Acid, to review progress in the last decade in European countries in terms of developing and implementing public health policies to raise periconceptional folate status, and analyse data on the prevalence of neural tube defects to determine the extent to which neural tube defects have been prevented up to the year 2002. Representatives from seventeen countries participating in EUROCAT provided information about policy, health education campaigns and surveys of folic acid supplement uptake in their country. By the end of 2005, 11 of 18 countries had an official policy advising women to take periconceptional supplements. Two countries advised dietary means only to raise folate consumption. Half the countries had implemented a health education campaign to reach women directly. Surveys showed that in all countries, a minority of women were taking supplements during the entire advised periconceptional period, with supplementation rates varying from 5% to 46% between countries. The situation regarding lack or low uptake of supplementation advice is reflected in the lack of a clear decline in the prevalence of neural tube defects across Europe. In the UK and Ireland, it was difficult to distinguish any effect of supplementation policy against the background of a strongly declining NTD prevalence throughout the 1980s, predating folic acid advice.

We conclude that 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 avoid widening socio-economic inequalities in NTD prevalence and result in large scale prevention of NTDs. A survey of parent support groups relating to neural tube defects is ongoing to assess their support for folic acid fortification.

In view of the findings that there has been a lack of substantial decline in neural tube defect prevalence in Europe since 1991, and even countries which have pursued supplementation policies relatively actively have found a limited preventive impact, EUROCAT has issued the following recommendations:

1) Countries should review their policies regarding folic acid fortification and supplementation, taking account of WHO Europe recommendations.

2) European countries could prevent most neural tube defects in planned pregnancies by putting in place an official policy recommending periconceptional folic acid supplementation and taking steps to ensure that the population are aware of the benefits of supplementation and the importance of starting supplementation **before** conception.

3) As many pregnancies are unplanned, European countries could achieve more effective prevention of neural tube defects by additionally introducing fortification of a staple food with folic acid. The particular objectives of this policy would be preventing neural tube

defects among women who do not plan their pregnancy, and reducing socio-economic inequalities in neural tube defect prevalence.

4) Health effects of supplementation and fortification should be monitored, and policies should be reviewed periodically in light of the findings.

5) The European population should be covered by high quality congenital malformation registers which collect information about affected pregnancies (livebirths, stillbirths and terminations for fetal abnormality). One important use for the information would be to assess the effect of folic acid supplementation and fortification on NTD rates as well as rates of other congenital malformations.

Further details can be found in the following publications:

Abramsky L, Busby A, Dolk H (2005), "Promotion of Perinconceptional Folic Acid has had Limited Success", *Journal of the Royal Society for the Promotion of Health*, Vol 125, No 5, pp 206-208.

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.

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.

EUROCAT (2005) EUROCAT Special Report: Prevention of Neural Tube Defects by Periconceptional Folic Acid Supplementation in Europe. *EUROCAT Central Registry*, University of Ulster. (www.eurocat.ulster.ac.uk/pubdata/Folic-Acid.html)

Dolk H (2005), "Strategies for Prevention", *European Conference on Rare Diseases*, Luxembourg 21-22 June, pp 165-167.

Prenatal diagnosis of congenital anomalies

Prenatal diagnosis of congenital anomaly may lead to preparation for the birth of an affected child by the family and health services, or in severe cases to termination of the pregnancy. Information on the number of terminations of pregnancy following prenatal diagnosis is available on the EUROCAT website, and can also be seen in Table 2.

European countries currently vary widely in the provision and uptake of prenatal screening and diagnosis and its quality, as well as the “culture” in terms of decision to carry on the pregnancy. This contributes to variation between countries in childhood prevalence and in perinatal and infant mortality. A wide range of publications during 2004-5 deal with these issues:

EUROCAT Special Report (2005) “Prenatal Screening Policies in Europe”, *EUROCAT Central Regisytry*, University of Ulster. (http://www.eurocat.ulster.ac.uk/pdf/Special-Report-Prenatal-Diagnosis.pdf)

Garne E, Loane M, de Vigan C, Scarano G, de Walle H, Gillerot Y, Stoll C, Addor M-C, Stone D, Gener B, Feijoo M, Mosquera-Tenreiro C, Gatt M, Queisser-Luft A, Baena N and Dolk H, (2004), "Prenatal Diagnostic Procedures Used in Pregnancies with Congenital Malformations in 14 Registries in Europe", *Prenatal Diagnosis*, Vol 24, No 11, pp 908-912

Garne E, Loane M, Dolk H, de Vigan C, Scarano G, Tucker D, Stoll C, Gener B, Pierini A, Nelen V, Rösch C, Gillerot Y, Feijoo M, Tincheva R, Queisser-Luft A, Addor M-C, Mosquera C, Gatt M, Barisic I (2005) "Prenatal diagnosis of Severe Structural Malformations in Europe", *Ultrasound in Obstetrics and Gynecology (UOG),* Vol 25, No 1, pp 6-11.

Baena N, De Vigan C et al (2004), "Turner Syndrome: Evaluation of Prenatal Diagnosis in 19 European Registries", *American Journal of Medical Genetics,* Vol 129A, No 1, pp 16-20.

Wellesley D, De Vigan C, Baena N, Cariati E, Stoll C, Boyd P, Clementi M and the EUROSCAN Group (2004), "Contribution of Ultrasonographic Examination to the Prenatal Detection of Trisomy 21: Experience from 19 European registers", *Annals de Genetique,* Vol 47, No 4, pp 373-380.

Wiesel A, Queisser-Luft, A, Clementi M, Bianca S, Stoll C and the EUROSCAN Study Group (2005), "Prenatal Detection of Congenital Renal Malformations by Fetal Ultrasonographic Examination: An Analysis of 709,030 Births in 12 European Countries", *European Journal of Medical Genetics,* Vol 48, pp 131-144.

The situation regarding Down Syndrome is a special one. The total number of affected pregnancies is increasing due to the rise in maternal age across Europe, but counteracting this in terms of livebirths the proportion of affected fetuses prenatally diagnosed leading to termination of pregnancy has also increased. An analysis up to 1999 was published, and an update to 2004 will be available in 2006. Since 1980, the proportion of births to mothers of 35 years of age and over has risen quite dramatically. By 1995-99, 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 1,000 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 in 1995-99 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 livebirth prevalence has since 1980 increasingly diverged from the rising total prevalence, in some areas remaining approximately stable, in others decreasing over time. The joint influences of maternal age and prenatal screening have led to significant and changing geographic inequalities in Down Syndrome livebirth prevalence in Europe.

Dolk H, Loane M, Garne E, De Walle H, Queisser-Luft A, De Vigan C, Addor MC, Gener B, Haeusler M, Jordan H, Tucker D, Stoll C, Feijoo M, Lillis D, Bianchi F. Trends and geographic inequalities in the livebirth prevalence of Down Syndrome in Europe 1980-1999. Revues Epidem Sante Publique 2005; 53:1-9.

EUROCAT has supplied data which independently confirmed the findings of the England and Wales Down Syndrome register that the maternal age specific rates of Down Syndrome for women of 44 years and over level off, rather than continuing to increase exponentially as previously assumed. This has implications for prenatal screening among these mothers:

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.

Reports are in preparation of a number of other prenatal –diagnosis related studies:

The impact of prenatal diagnosis of Transposition of Great Arteries on postnatal outcome.
The impact of prenatal diagnosis on gestational age at birth of babies with gastrointestinal anomalies.

Terms of reference 4:
To promote the exchange of experience on population-based registration methods, classification and coding of congenital anomalies, and surveillance methods.

The 19th and 20th annual Registry Leaders Meetings were held in Bergen, Norway (2004) and Poznan, Poland (2005) the latter together with the 8th European Symposium on the Prevention of Congenital Anomalies. In Poland in particular, the participation of new colleagues from Central and Eastern Europe was welcomed (Ukraine, Latvia, Byelorussia and Moscow).

Two malformation coding workshops were run in 2005 (London and Dublin).

In order to facilitate data transmission to the Central Registry, the EUROCAT Data Management Programme ("EDMP") is available in Microsoft Access. This interfaces with the EUROCAT Central Database. New versions are downloadable from the membership area of the EUROCAT website, and a copy is provided to all new members. The EDMP allows a choice between data entry or data import, and runs a standard validation programme on data which is expanded over time to ensure progress toward higher quality data and greater data standardisation. Data can be exported in standard format for transmission to EUROCAT Central Registry. The programme includes a facility for defining EUROCAT subgroups on the basis of ICD9 or 10 codes, outputting standard tables, and running statistical monitoring tests. "Clinics" to train in the use of the EDMP are held at each Registry Leaders Meeting.

A number of revisions have been made to the EUROCAT standard dataset and to the definition of congenital anomaly subgroups:

> EUROCAT (2005), "EUROCAT Guide 1.3: Instruction for the Registration of Congenital Anomalies", *EUROCAT Central Registry*, University of Ulster. (http://www.eurocat.ulster.ac.uk/pubdata/Guide%201.3.html)

Two coding guides have been published:

> EUROCAT (2004), "EUROCAT Guide 3 (2nd Ed): For the Description and Classification of Congenital Limb Defects", *EUROCAT Central Registry*, University of Ulster. (http://www.eurocat.ulster.ac.uk/pubdata/Publications.html#EUROCAT%20Coding%20Guides)

> EUROCAT (2005), "EUROCAT Guide 6: Definition and Coding of Syndromes", *EUROCAT Central Registry*, University of Ulster (http://www.eurocat.ulster.ac.uk/pubdata/Publications.html#EUROCAT%20Coding%20Guides)

Work on aetiologic classification has resulted in a suggested scheme published in:

> Wellesley D, Boyd P, Dolk H, Pattenden S (2005), "An Aetiological Classification of Birth Defects for Epidemiological Research", *Journal of Medical Genetics*, Vol 42, No 1, pp 54-57.

The Coding and Classification Committee is working on two issues regarding ICD coding. One is how to remain compatible with ICD-10 updates, which are implemented differently in different countries. The other is providing feedback for WHO ICD coding revisions, both 10th and 11th versions. The committee is also starting to work with the Rare Diseases Task Force of the European Union and the WHO on the development of coding systems for rare diseases, compatible with ICD developments.

The development of Data Quality Indicators is an important part of EUROCAT activity. A standard set of 30 data quality indicators has been developed, to be used in addition to registry descriptions. This is an important new area for the evaluation of congenital anomaly registries, and wider dissemination will take take place in 2006-7.

A special study evaluating the quality of the England and Wales congenital anomaly notification scheme was undertaken by English EUROCAT registers, documenting major deficiencies in the completeness of ascertainment of affected births, and the need for the national system to incorporate data on terminations of pregnancy:

> 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.

In recent years, the issue of parent consent for registration of affected individuals has been raised in a number of European countries. A survey was carried out in 2003 of current practice which has since been published:

> 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.

Registries note that the requirement for parental consent (unless operated on an opt-out basis) is a grave logistic difficulty, with considerable resource implications, and a considerable actual or potential impact on case ascertainment. Experience is that while parents rarely refuse permission, underascertainment comes about through clinicians not asking consent, as this requires clinical time and more paperwork, and must be co-ordinated between clinicians to avoid repeatedly asking for notification consent. In some countries, particularly Scandinavian countries, there are legal provisions for registration without consent, but with a strong emphasis on data protection.

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