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INDICATORS FROM OTHER EUROPEAN NETWORKS

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8.1 EUROCAT: PREVALENCE OF CONGENITAL ANOMALIES (R1)

1. INTRODUCTION

Collectively, congenital anomalies have an important public health impact in terms of their effect on the quality of life of affected children and adults and their families, their contribution to fetal and infant mortality (both in terms of loss of potential years of life and emotional costs to the family), the provision, quality, and financial cost of medical, social, and educational services to improve the participation and quality of life of affected individuals and their families, and the provision, quality, and financial cost of prenatal screening in the population, as well as its psychological cost to pregnant women.

Congenital anomalies can be caused by genetic or environmental factors or an interaction of both. The precise cause of congenital anomalies is not known for the majority. In EUROCAT data, 1.85% of congenital anomaly cases are recorded as monogenic syndromes, 13% as chromosomal anomalies, and 0.65% as teratogenic syndromes caused by maternal infections, drugs, or alcohol. Although genetic factors play an important role, it is by changing environmental exposures that we can prevent congenital anomalies.[1]

Congenital anomalies straddle different public health agendas — perinatal and child health, rare diseases,[1] environmental health, drug safety surveillance, and major health determinants. Many major "lifestyle" determinants of ill health in the population, such as alcohol, recreational drugs, smoking, and obesity, are also risk factors for congenital anomalies. Any strategy to tackle these health determinants should pay special attention to women of childbearing age, remembering that the harm is often done in very early pregnancy before the pregnancy is recognised and that the fetus may have special susceptibility. Policies aimed at ensuring "healthy pregnancy" or good perinatal outcomes include congenital anomalies as part of a range of outcomes, including fetal and infant mortality, birth weight, and neurodevelopmental outcomes. However, a system of preconceptional and periconceptional care is needed for congenital anomalies. Much greater investment is needed in postmarketing surveillance of medicinal drugs and assisted reproduction technologies (ART), and in environmental health surveillance, particularly of sources of environmental pollution that may have the potential to harm the fetus.

2. EPIDEMIOLOGIC SURVEILLANCE OF CONGENITAL ANOMALIES

Congenital ("present from birth") anomalies, which involve structural malformations diagnosed prenatally, at birth, or within the first year of life, are the focus of epidemiologic surveillance through congenital anomaly registries. EUROCAT (European Surveillance of Congenital Anomalies) is the principal source of information on the epidemiology of congenital anomalies in Europe. EUROCAT is a network comprising almost all of the population-based congenital anomaly registries in Europe. It currently surveys more than 1.7 million births per year in Europe, covered by 37 registries in 21 countries. Using multiple sources of information to collect high quality data (both in terms of case ascertainment and diagnostic detail), registries record cases of all major structural congenital and chromosomal anomalies (standard EUROCAT congenital anomaly subgroups).[2] EUROCAT registries cover affected live births, fetal deaths from 20 weeks of gestation (including stillbirths), and terminations of pregnancy for a fetal anomaly (TOPFA) following prenatal diagnosis (whether before or after 20 weeks of gestation). Registries may cover only diagnoses made prenatally and in infancy, or extend registration to new diagnoses

made during childhood. Using common software, each member registry transmits a standard dataset to a central database at the EUROCAT Central Registry, where further quality validation is performed. By October, 2012, the EUROCAT database contained 431 048 anonymised cases. The EUROCAT system and process are described in EUROCAT report 9.[3-9]

The main issues for surveillance by EUROCAT are (i) the identification of environmental risk factors and high risk groups, which leads to opportunities for prevention;[10-16] (ii) the evaluation of preventive strategies (such as periconceptional folic acid supplementation)[17-19] (iii) the estimation of the numbers of children and families requiring specialist health or other services;[20-22] and (iv) evaluation of the impact of prenatal screening and diagnostic services.[23, 24]

Within Europe, there are geographic and socioeconomic inequalities in the prevalence of congenital anomalies. These are now of 2 main types — variation in the prevalence of risk factors affecting total prevalence and additional variation in prenatal detection and TOPFA rates affecting prevalence among live births.

3. POPULATION COVERAGE BY EUROCAT

EUROCAT started in 1979. In 2010 there were 39 (full and associate) EUROCAT member registries in 21 countries covering 29.6% of births across the 27 EU member states (Table 8.1), in addition to coverage in 4 non-member states — Norway, Switzerland, Croatia, and Ukraine (Table 8.1). Moldova and Slovenia are affiliate member registries and Slovakia is working towards full membership in 2014.

Maintaining high quality data usually requires a limit to the total size of the population to be covered by a register. Thus, there is a preference in larger nations for regional rather than national registries, networked nationally, and networked at a European level by EUROCAT. The proportion of national births covered by registries in each country is shown in Table 8.1, ranging among those countries participating from 3% (Germany) to 100% (Czech Republic, Norway, Poland, Sweden, Finland, Malta, and Hungary). Although complete coverage of the European population may be an ideal, it should not replace deeper investment of resources in areas already covered — excellent data from one quarter of Europe will give us more meaningful information than poor data from all of Europe.

4. PREVALENCE OF CONGENITAL ANOMALIES IN EUROPE

EUROCAT recorded a total prevalence of major congenital anomalies of 25.5 per 1000 births for 2006-2010 (Table 8.2). Extrapolating to the entire EU-27 in 2010, this represents approximately 140 000 cases. Total prevalence includes live births, fetal deaths after 20 weeks of gestation (including stillbirths), and TOPFA following prenatal diagnosis. Major congenital anomalies are those associated with high mortality or other serious medical or functional consequences, as defined by EUROCAT guidelines.[2] The prevalence of major congenital anomalies among live births recorded by EUROCAT was 20.9 per 1000 births for 2006-2010 (Table 8.2). Extrapolating to the entire EU-27, this represents approximately 112 000 affected live births.

Congenital heart defects are the most common subgroup, with total prevalence of 8.1 per 1000 births including ventricular septal defects (3.4 per 1000), followed by limb defects (4.1), chromosomal defects (3.6), and defects of the urinary system (3.3) and nervous system (2.5). The total prevalence of chromosomal anomalies was 3.6 per 1000 births (Table 8.2).

The EURO-PERISTAT indicators include 3 congenital anomaly subgroups: cleft lip (with or without palate), spina bifida, and Down syndrome. Total prevalence for these anomalies by country is shown in Figure 1. Further data (including confidence intervals) about these conditions can be found on EUROCAT's website tables, reported by pregnancy outcome and year of birth.

Anonymous aggregate prevalence data (updated biannually) can be interrogated, by registry, year, and congenital anomaly of interest, via the interactive EUROCAT website prevalence tables (available at http://www.eurocat-network.eu/accessprevalencedata/prevalencetables). In April 2013, the website data was updated to birth year 2011. The prevalence of selected monogenic syndromes in Europe can also be accessed via the same link.

The latest EUROCAT perinatal mortality data can be viewed on the Key Public Health Indicator section of the EUROCAT website (available at: http://www.eurocat-network.eu/accessprevalencedata/keypublichealthindicators).

Prenatal detection rates for the latest 5-year period, created from surveillance data collected by EUROCAT member registries, can be viewed at any time (available at: http://www.eurocat-network.eu/prenatalscreeninganddiagnosis/prenataldetection(pd)rates).

5. TERMINATION OF PREGNANCY FOR FETAL ANOMALIES

Some congenital anomalies in Europe are very commonly prenatally diagnosed. For example EUROCAT data for 2006-2010 show the proportion of total cases prenatally diagnosed was 96% for anencephalus, 82% for spina bifida, 70% hypoplastic left heart, 91% gastroschisis, 88% bilateral renal agenesis (including Potter syndrome), and 63% Down syndrome (Table 8.3).

For some anomalies, including various forms of congenital heart defects, gastroschisis, and diaphragmatic hernia, prenatal diagnosis leads to better preparation of families and health services for an affected baby and can improve treatment success.[23, 24]

For other anomalies, particularly neural tube defects and chromosomal anomalies, including Down syndrome, prenatal diagnosis is commonly followed by TOPFA.

The reported TOPFA rate varies from 0 (Ireland and Malta, where TOPFA is illegal) to 10.5 (Paris, France) per 1000 births (Table 8.4). Differing prenatal screening policies and practices, differences in uptake of prenatal screening due to cultural and organisational factors, and differences in TOPFA laws and practices all influence the rate of TOPFA in the population.[23, 24] Some countries allow TOPFA at any gestational age. Others have an upper gestational age limit, and yet others have an upper gestational age limit but allow TOPFA for lethal anomalies beyond this limit.[23]

Of all TOPFA in 2006-2010 (all EUROCAT full member registries combined), 16% were for neural tube defects (7% anencephaly and 7% spina bifida) and 26% for Down syndrome (Table 8.2). Table 8.4 shows TOPFA before and after 20 weeks of gestation. The highest TOPFA rate for both periods is recorded in Paris (France) (6.29 and 4.24 per 1000 births respectively) (Table 4). Comparison between countries is complicated by different laws and practices regarding the recording of late terminations. Late TOPFA, where legal, may be recorded as stillbirths or as live births with neonatal death in some countries.

Differences between countries in the proportion of cases prenatally diagnosed leading to TOPFA lead to wide variations in live birth rates of certain congenital anomalies. The live birth rate of spina bifida (2006-2010) varies from 0.04 per 1000 births in Denmark to 0.93 in Malta. The livebirth rate of Down syndrome, which is in addition influenced by the maternal age profile of the population, varies from 0.38 per 1000 births in Portugal to 2.3 in Ireland.

6. FETAL AND NEONATAL MORTALITY ASSOCIATED WITH CONGENITAL ANOMALIES

Congenital anomalies are an important contributor to perinatal mortality. In EUROCAT the overall recorded rate of late fetal deaths/stillbirths with congenital anomalies is 0.44 per 1000 births for the period 2006-2010, and the rate of deaths in the first week is 0.36 per 1000 births, resulting in a total perinatal mortality rate of 0.81 per 1000 births associated with congenital anomalies (Table 8.5). The main congenital anomaly subgroups contributing to perinatal mortality in 2006-2010 were chromosomal anomalies (27% of perinatal deaths had a chromosomal anomaly), congenital heart defects (24%), and nervous system anomalies (16%) (Table 8.6). Chromosomal anomalies contribute more to stillbirths than to deaths during the first week, while congenital heart defects contribute more to deaths during the first week than to stillbirths. Anomalies of the nervous system contribute slightly more to deaths during the first week than to stillbirths (Table 8.5).

Perinatal mortality associated with congenital anomalies varies by country (Table 8.6). The rates vary from 0.27 per 1000 births in Portugal to 1.11 in Switzerland.

In most countries, TOPFA far outnumber stillbirths and neonatal deaths with congenital anomalies (Table 8.4). Up to 1.1% (France) of fetuses result in a TOPFA, stillbirth, or early neonatal death associated with a congenital anomaly, and 5 countries record rates above 0.5% for an overall rate of 6.3 per 1000 (Table 8.4). The differences in total mortality (TOPFA + perinatal death) between countries probably mainly reflects the frequency with which TOPFA is carried out for non-lethal anomalies, but is also influenced by differences between countries in the prevalence of anomalies such as neural tube defects and Down syndrome and in the completeness of ascertainment of stillbirths, neonatal deaths, and TOPFA.

Despite the important mortality consequences of congenital anomalies, the vast majority of cases of congenital anomalies across Europe are liveborn children who survive infancy, but who may have important medical, social, or educational needs.

7. STATISTICAL MONITORING FOR TRENDS AND CLUSTERS

EUROCAT annually performs statistical monitoring for the rates of congenital anomalies over time, to enable the detection of signals of new or increasing teratogenic exposures that require public health action.

EUROCAT's Annual Statistical Monitoring Reports can be accessed online via the EUROCAT website homepage (www.eurocat-network.eu).

The EUROCAT Statistical Monitoring Report for 2010 describes statistical monitoring of both clusters and trends in Europe for the 10-year period 2001-2010 (http://www.eurocat-network.eu/clustersandtrends/statisticalmonitoring/statisticalmonitoring-2010).

Key findings from the pan-Europe (all EUROCAT registries combined) analyses in 2010 were:

- Rates of neural tube defects (NTDs) declined on average by 1.7% per year, with rates for spina bifida declining on average by 2.1% per year.
- There was a decreasing trend detected over time for the subgroup of congenital heart defects (CHD). However, increasing trends were detected in 2 of the more severe types of CHD: tetralogy of Fallot increased on average by 2.3% per year, and single ventricles increased on average by 5.9% per year.
- Increasing trends were found for the following digestive anomalies: oesophageal atresia with or without trachea-oesophageal fistula, duodenal atresia and stenosis, and atresia and stenosis of other parts of the small intestine. In contrast, atresia of bile ducts decreased by an average of 9% per year.
- The prevalence of the abdominal wall defect gastroschisis increased on average by 1.6% per year. Four out of the 5 registries with the highest prevalence rates were located in the UK.
- Prevalence of the 3 chromosomal autosomal trisomies increased on average by 1.0% to 2.4% per year (Down syndrome, 1%; Edward syndrome, 2.3%; Patau syndrome, 2.4%). This increase in prevalence is explained by the increase in the proportion of older mothers giving birth.
- Investigation of clusters in the last 2 years (for 2009-2010) identified no clusters of immediate public health concern. The Taskforce for the Evaluation of Clusters (TEC) continues to be available for consultation on clusters identified by statistical monitoring.
- The report also published the findings of a survey on local dissemination of the Annual Statistical Monitoring report. Two thirds (68%) of registries reported submitting the report findings to the relevant person within their public health system.

8. CONGENITAL ANOMALIES IN MULTIPLE BIRTHS

EUROCAT has recently analysed the prevalence and relative risk of congenital anomalies in multiple births for the period 1984-2007.[10] In the European population studied, the multiple birth rate rose by approximately 50%. Of the 5.4 million births covered, 3.0% of babies were from multiple births. Of the total number of major congenital anomaly cases (148 359), 3.83% were from multiple births. The prevalence of congenital anomalies from multiple births increased from 0.6 (1984-1987) to 1.1 (2004-2007) per 1000 births. The risk of congenital anomalies was 27% higher in multiple than singleton births, with this risk increasing over time, potentially related to ART rather than multiple birth status. Multiple births with congenital anomalies were more than twice as likely to be stillbirths compared to singleton births (4.6% compared to 1.8%) and more than twice as likely to be early neonatal deaths (5.45% compared to 2.51%). However, cases from multiple pregnancies were less likely to be TOPFA. The co-occurrence of multiple births and congenital anomalies among liveborn infants places particular demands on parents and health services. This may be even more relevant for the 1 in 9 affected twin pairs where both babies have a congenital anomaly. The increase in multiple birth rates may be explained by changes in maternal age and increased use of ART. More research needs to be done to determine the contribution of ART to the risk of congenital anomalies in multiple births.

9. TRENDS IN CHROMOSOMAL ANOMALIES RELATING TO INCREASES IN MATERNAL AGE

EUROCAT has recently analysed trends in the prevalence of Down syndrome and other trisomies for the period 1990 to 2009.[13] The proportion of births to mothers aged 35 years and older in Europe increased from 13% in 1990 to 19% in 2009, and this has led to an increase in rates of Down syndrome, Edward syndrome, and Patau syndrome (3 chromosomal anomalies). Data showed that, in Europe, women over 40 have a risk of having a Down syndrome baby 17 times

higher than do women aged 25-29 years. Edward and Patau syndromes are much rarer (both combined will occur in 1 in every 1400 pregnancies), are severe, and have high perinatal mortality. They have a similar increased risk for older mothers. Across Europe, over half the babies with Down syndrome have mothers older than 34 years of age. While the total rates for these 3 syndromes have increased steadily since 1990, the number of cases resulting in a live birth has remained stable over time in Europe. This is largely due to the increased rate of prenatal diagnosis and subsequent TOPFA. Approximately 50% of cases with Down syndrome, 70% of cases with Edward syndrome, and 70% of Patau syndrome cases resulted in a TOPFA, although this varied widely by country. The live birth rates of Down syndrome also varied; they were lowest in Spain and Switzerland and highest in Ireland and Malta, where termination of pregnancy is illegal. From a public health perspective, this is important for assessing the impact of delayed childbearing and prenatal screening programmes as well as for planning health care for mothers and for children with Down syndrome.

10. EUROmediCAT

In 2007-2009 EUROCAT performed case-control studies using EUROCAT data to address and evaluate hypotheses (or signals) generated from the literature about the teratogenicity of antiepileptic drugs (AEDs), of both the newer generation (lamotrigine[25]) and the older generation (valproic acid[16] and carbamazepine[15]). An AED database was created for this, covering 3.9 million total births (19 registries, 1995-2005), including 98 075 with congenital anomalies (live births, stillbirths, and TOPFA).

The lamotrigine study responded to a signal from the North American AED cohort that indicated a more than 10-fold risk of orofacial clefts with lamotrigine. The study did not support the original signal. Valproic acid was known to be teratogenic, but with which birth defects it is specifically associated was unknown — 7 of 14 birth defects were confirmed as significantly associated with valproic acid exposure, with risk increases up to 13-fold. This was the first study to identify specific types of birth defects caused, and its implications go beyond clinical practice, to the elucidation of teratogenic mechanisms of action. The carbamazepine study proceeded as for valproic acid, but in contrast confirmed only one significantly associated birth defect — spina bifida, with much less risk than for valproic acid.

Following on from these studies, EUROCAT's daughter project EUROmediCAT, which commenced in 2011 (http://euromedicat.eu/), has begun to contribute to the development of a pharmacovigilance system in Europe. EUROCAT is also further analysing the EUROCAT data in relation to antidepressant safety, and EUROmediCAT is looking further at newer generation AEDs, insulin analogs, and antiasthmatic drugs.

11. THE FUTURE

The last few decades have not seen any real progress in primary prevention of congenital anomalies, as evidenced by the lack of decline in prevalence. Implementation of current knowledge with effective policies and research into causes of congenital anomalies, if combined with political will, have the potential to change this situation. Primary prevention is a main goal of the EUROCAT Joint Action (2011-2013), cofunded by the EC, under the framework of the EU Health Programme 2008-2013, Grant Agreement 2010 22 04 (Executive Agency for Health & Consumers). EUROCAT is collecting data on current policies in the EU member states for primary prevention of congenital anomalies and proactively liaising with the European Project for Rare Diseases National Plans Development (EUROPLAN) to indicate the areas that member states might target in their strategies for primary prevention of congenital anomalies.[19]

Clusters of congenital anomalies and their potential relations to environmental pollution or to newly marketed drugs are the most prominent public health concern about congenital anomalies, whether detected by the community or by surveillance. They require epidemiologic preparedness (see EUROCAT's Taskforce for the Evaluation of Clusters, http://www.eurocat-network.eu/clustersandtrends/clusteradvisoryservice/introduction) and further investment and co-operation between countries in cluster response, with effective dialogue with communities. However, primary prevention of congenital anomalies needs to be proactive as well as reactive.

EUROCAT's daughter project EUROmediCAT is contributing to the development of a pharmacovigilance system in Europe.

Prenatal screening and diagnosis have seen rapid development. The near future will bring less invasive technologies for the detection of chromosomal anomalies, and greater sensitivity and specificity of diagnosis of anomalies. Variations in the quality of screening services within Europe need examination. Another challenge for European countries is to reduce the number of women who may need to consider termination of pregnancy as an option by achieving effective primary prevention and improving the outcome of affected children and their families in terms of health, quality of life, and participation. It is vital to invest in the epidemiologic surveillance of congenital anomalies across Europe in order to direct and track our progress in these areas.

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Table 8.1 Coverage of the European population, birth year 2010, by EUROCAT full or associate member registries

Country	EUROCAT Registry	Year started EUROCAT data transmission	Annual Births 2010, Registry	Annual Births 2010, Country[1]	% Country Covered
EU (Present EU member states)			1 588 051	5 361 874	29.6
Belgium	Antwerp	1990	21 445		
	Hainaut	1980	12 403		
	Total		33 848	126 827	26.7
Bulgaria				75 637	0.0
Czech Republic	Czech Republic[2, 3]	2000	117 153	117 153	100.0
Denmark	Odense	1980	5059	63 096	8.0
Germany	Mainz	1990	3168		
	Saxony-Anhalt	1987	17 363		
	Total		20 531	678 959	3.0
Estonia				15 813	0.0
Ireland	Cork & Kerry	1996	10 248*		
	Dublin	1980	27 815*		
	South East	1997	7969*		
	Total		46 032	73 720	62.4
Greece				114 182	0.0
Spain	Barcelona	1992	14 862*		
	Basque Country	1990	21 246		
	Spain Hospital Network[2]	1980	87 086		
	Valencia Region	2007	51 739		
	Total		174 933	482 885	36.2

Table 8.1 (Continued)

Country	EUROCAT Registry	Year started EUROCAT data transmission	Annual Births 2010, Registry	Annual Births 2010, Country[1]	% Country Covered
France	French West Indies	2009	10 456		
	Isle de la Reunion	2002	14 543*		
	Paris	1981	27 400		
	Rhone-Alpes[2]	2006	60 083		
	Strasbourg	1982	13 239*		
	Total		125 721	834 559	15.1
Italy	Emilia Romagna	1981	42 154		
	Tuscany	1980	30 836		
	Total		72 990	561 165	13.0
Cyprus				9959	0.0
Latvia				19 336	0.0
Lithuania				35 954	0.0
Luxembourg				5824	0.0
Hungary	Hungary[3]	1998	90 722	90 722	100.0
Malta	Malta[3]	1986	4036	4036	100.0
Netherlands	Northern	1981	17 569	183 982	9.5
Austria	Styria	1985	10 442	78 728	13.3
Poland	Wielkopolska	1999	40 396		
	Rest of Poland[2, 3]	1999	371 811		
	Total		412 207	412 207	100.0
Portugal	South	1990	21 202	101 058	21.0
Romania				212 476	0.0
Slovenia				22 312	0.0
Slovakia				60 217	0.0
Finland	Finland[2, 3]	1993	61 161	61 161	100.0
Sweden	Sweden[2, 3]	2001	114 480	114 890	99.6
UK	E Mid & S York	1998	75 698		
	Northern England	2000	34 461		
	South West England	2005	51 328		
	Thames Valley	1991	31 321		
	Wales	1998	36 142		
	Wessex	1994	31 135		
	Total		260 085	806 351	32.3
Non EU					
Croatia	Zagreb	1983	6870*	43 372	15.8
Norway	Norway[3]	1980	62 770	62 770	100.0
Switzerland	Vaud	1989	8169	80 194	10.2
Ukraine	Ukraine[4]	2005	31 094	494 408	6.3

1 Source: EUROSTAT crude birth rate (accessed 06-03-2012)
http://epp.eurostat.ec.europa.eu/portal/page/portal/population/data/main_tables
2 Associate EUROCAT Registries (transmit aggregate data only)
3 Source of annual births in country provided by registry rather than EUROSTAT
4 http://www.ukrstat.gov.ua/operativ/operativ2010/ds/kn/kn_e/kn1210_e.html (accessed 12-03-2012)
*Provisional estimated figures provided by the registry

Table 8.2 Prevalence rates (per 1000 births) of EUROCAT congenital anomaly subgroups (2006-2010), for all EUROCAT full member registries combined*

Anomaly	LB Rate (per 1000 births)	LB+FD+TOPFA
Rate^ (per 1000 births)	20.89	25.51
Nervous system	1.23	2.47
Neural tube defects	0.25	0.95
Anencephalus and similar	0.03	0.35
Encephalocele	0.03	0.12
Spina bifida	0.19	0.48
Hydrocephalus	0.33	0.59
Microcephaly	0.23	0.26
Arhinencephaly/holoprosencephaly	0.03	0.13
Eye	0.38	0.41
Anophthalmos/microphthalmos	0.09	0.10
Anophthalmos	0.02	0.02
Congenital cataract	0.12	0.12
Congenital glaucoma	0.04	0.04
Ear, face, and neck	0.17	0.20
Anotia	0.03	0.03
Congenital heart defects	7.31	8.05
Severe CHD§	1.64	2.04
Common arterial truncus	0.05	0.07
Transposition of great vessels	0.31	0.35
Single ventricle	0.05	0.08
Ventricular septal defect	3.21	3.41
Atrial septal defect	2.27	2.31
Atrioventricular septal defect	0.28	0.39
Tetralogy of Fallot	0.28	0.32
Tricuspid atresia and stenosis	0.04	0.06
Ebstein anomaly	0.04	0.05
Pulmonary valve stenosis	0.39	0.40
Pulmonary valve atresia	0.08	0.10
Aortic valve atresia/stenosis§	0.11	0.12
Hypoplastic left heart	0.15	0.27
Hypoplastic right heart§	0.03	0.05
Coarctation of aorta	0.34	0.37
Total anomalous pulmonary venous return	0.06	0.06
PDA as only CHD in term infants (>=37 weeks)	0.38	0.38
Respiratory	0.47	0.63
Choanal atresia	0.08	0.08
Cystic adenomatous malformation of lung§	0.07	0.08

Table 8.2 (Continued)

Anomaly	LB Rate (per 1000 births)	LB+FD+TOPFA
Oro-facial clefts	1.32	1.47
Cleft lip with or without palate	0.79	0.89
Cleft palate	0.54	0.58
Digestive system	1.53	1.77
Oesophageal atresia with or without tracheo-oesophageal fistula	0.22	0.25
Duodenal atresia or stenosis	0.12	0.13
Atresia or stenosis of other parts of small intestine	0.09	0.09
Ano-rectal atresia and stenosis	0.25	0.31
Hirschsprung's disease	0.12	0.12
Atresia of bile ducts	0.03	0.03
Annular pancreas	0.02	0.02
Diaphragmatic hernia	0.21	0.28
Abdominal wall defects	0.37	0.64
Gastroschisis	0.24	0.29
Omphalocele	0.12	0.29
Urinary	2.85	3.34
Bilateral renal agenesis including Potter syndrome	0.03	0.12
Renal dysplasia	0.31	0.41
Congenital hydronephrosis	0.95	1.01
Bladder exstrophy and/or epispadia	0.05	0.07
Posterior urethral valve and/or prune belly	0.07	0.09
Genital	2.15	2.22
Hypospadias	1.79	1.81
Indeterminate sex	0.05	0.07
Limb	3.69	4.12
Limb reduction	0.36	0.52
Upper limb reduction	0.25	0.36
Lower limb reduction	0.12	0.20
Complete absence of a limb	0.00	0.02
Club foot - talipes equinovarus	0.94	1.07
Hip dislocation and/or dysplasia	0.78	0.78
Polydactyly	0.83	0.89
Syndactyly	0.48	0.51
Skeletal dysplasias[§]	0.09	0.18
Craniosynostosis	0.20	0.21
Congenital constriction bands/amniotic band	0.03	0.05
Situs inversus	0.05	0.06

Table 8.2 (Continued)

Anomaly	LB Rate (per 1000 births)	LB+FD+TOPFA
Conjoined twins	0.00	0.02
Congenital skin disorders	0.15	0.16
Teratogenic syndromes with malformations§	0.10	0.13
Fetal alcohol syndrome§	0.05	0.05
Valproate syndrome§	0.01	0.01
Maternal infections resulting in malformations	0.04	0.06
Genetic syndromes + microdeletions	0.38	0.47
Sequences	0.14	0.23
Chromosomal	1.48	3.64
Down syndrome	0.97	2.12
Patau syndrome/trisomy 13	0.04	0.20
Edwards syndrome/trisomy 18	0.08	0.49
Turner syndrome	0.06	0.22
Klinefelter syndrome	0.04	0.08

LB = Live Births
FD = Fetal Deaths/stillbirths from 20 weeks of gestation
TOPFA = Termination of pregnancy for a fetal anomaly following prenatal diagnosis
- = Data not available
§ = Incomplete or missing specification of ICD 9 codes
^ = Perinatal mortality rates associated with congenital anomalies as reported in EUROCAT database. Data not available

*cases and prevalence (per 1000 births) for the following registries (as of December 2012): Styria (Austria), Antwerp (Belgium), Hainaut (Belgium), Zagreb (Croatia), Odense (Denmark), French West Indies (France), Isle de la Reunion (France), Paris (France), Strasbourg (France), Mainz (Germany), Saxony-Anhalt (Germany), Hungary, Cork and Kerry (Ireland), Dublin (Ireland), SE Ireland, Emilia Romagna (Italy), Tuscany (Italy), Malta, N Netherlands (NL), Norway, Wielkopolska (Poland), S Portugal, Basque Country (Spain), Valencia Region (Spain), Vaud (Switzerland), East Midlands & South Yorkshire (UK), Northern England (UK), South West England (UK), Thames Valley (UK), Wales (UK), Wessex (UK), Ukraine, from 2006 - 2010

Table 8.3 Prenatal diagnosis of 18 selected congenital anomaly subgroups (2006-2010)

Malformation	Total Cases	Cases Prenatally Diagnosed (% of Total Cases)
Non-chromosomal		
All anomalies (excluding chomosomals)	75 751	22 573 (30%)
Anencephalus and similar (excluding chromosomals)	1232	1185 (96%)
Spina bifida (excluding chromosomals)	1577	1288 (82%)
Hydrocephalus (excluding chromosomals)	1914	1403 (73%)
Transposition of great vessels (excluding chromosomals)	1188	454 (38%)
Hypoplastic left heart (excluding chromosomals)	888	624 (70%)
Cleft lip with or without palate (excluding chromosomals)	2857	1379 (48%)
Diaphragmatic hernia (excluding chromosomals)	893	509 (57%)
Gastroschisis (excluding chromosomals)	993	904 (91%)
Omphalocele (excluding chromosomals)	730	596 (82%)
Bilateral renal agenesis including Potter syndrome (excluding chromosomals)	392	343 (88%)
Posterior urethral valve and/or prune belly (excluding chromosomals)	291	234 (80%)
Limb reduction (excluding chromosomals)	1626	811 (50%)
Club foot - talipes equinovarus (excluding chromosomals)	3678	1398 (38%)
Chromosomal		
Chromosomal	12 479	8765 (70%)
Down syndrome	7233	4538 (63%)
Patau syndrome/trisomy 13	685	625 (91%)
Edwards syndrome/trisomy 18	1709	1537 (90%)

Table 8.4 Rate of TOPFA and rates of perinatal deaths (per 1000 births) by country (2006-2010), for 13 EUROCAT full member registries

Centre	Prevalence TOPFA <20 Weeks per 1000 births	Prevalence TOPFA 20+ Weeks per 1000 births	Total Prevalence TOPFA per 1000 births	Perinatal Mortality per 1000 births	^Perinatal Mortality + TOPFA per 1000 births
Denmark (Odense)	4.44	2.00	6.44	0.72	7.16
France (Paris)	6.29	4.24	10.54	0.87	11.41
Italy (Tuscany)	2.70	1.39	4.42	0.30	4.71
Netherlands (North)	1.75	1.87	3.71	1.05	4.76
Switzerland (Vaud)	6.00	2.06	8.06	1.11	9.17
Portugal (South)	0.39	0.20	0.64	0.27	0.91
Spain (Basque Country, Valencia Region)	3.27	2.01	5.35	0.53	5.88
Germany (Saxony Anhalt)	2.07	1.23	3.35	0.96	4.31
Austria (Styria)	3.04	0.85	3.97	0.90	4.87
UK (Thames Valley, SW England, Wessex)	3.56	2.22	5.87	1.10	6.97
EUROCAT total	**3.33**	**2.02**	**5.44**	**0.81**	**6.25**

^Perinatal mortality+TOPFA is sum of previous 2 columns. All figures rounded to 2 decimal places.

Table 8.5 Gestational age and prevalence rate (per 1000 births) of TOPFA for all anomalies, by EUROCAT registry in 2010

Description	Breakdown by anomaly subgroup (as a % of all FDs)	Breakdown by anomaly subgroup (as a % of all LBs with death in 1st week)	Prevalence of FD per 1000 births	Prevalence of 1st week deaths per 1000 births	*Perinatal Mortality per 1000 births
All Anomalies	100.0	100.0	0.44	0.36	0.81
All Anomalies Excluding Chromosomal Anomalies	64.7	83.8	0.29	0.30	0.59
Nervous system	14.2	17.5	0.06	0.06	0.13
Neural Tube Defects	4.8	6.5	0.02	0.02	0.04
Congenital heart defects	17.7	31.0	0.08	0.11	0.19
Severe CHD §	8.8	19.7	0.04	0.07	0.11
Ventricular septal defect	3.5	5.8	0.02	0.02	0.04
Hypoplastic left heart	2.6	8.5	0.01	0.03	0.04
Respiratory	6.7	13.4	0.03	0.05	0.08
Digestive system	5.7	18.2	0.03	0.07	0.09
Diaphragmatic hernia	0.7	8.7	0.00	0.03	0.03
Urinary	10.1	18.4	0.04	0.07	0.11
Limb	12.3	11.0	0.05	0.04	0.09
Chromosomal	35.3	16.2	0.16	0.06	0.22
Down Syndrome	13.8	2.7	0.06	0.01	0.07
Edward syndrome/trisomy 18	7.9	5.8	0.04	0.02	0.06

*Perinatal mortality is sum of previous 2 columns. All figures rounded to 2 decimal places.
^ Odense, Paris, Tuscany, N Netherlands, Vaud, S Portugal, Basque Country, Valencia Region, Saxony Anhalt, Styria, Thames Valley, Wessex, SW England

Table 8.6 Perinatal mortality associated with congenital anomalies in 13 EUROCAT full member registries (2006-2010), by type of anomaly

Centre	Prevalence of FD per 1000 births	Prevalence of Early Neonatal Deaths per 1000 births	*Perinatal Mortality per 1000 births
Denmark (Odense)	0.49	0.23	0.72
France (Paris)	0.40	0.47	0.87
Italy (Tuscany)	0.17	0.13	0.30
Netherlands (North)	0.55	0.50	1.05
Switzerland (Vaud)	0.62	0.49	1.11
Portugal (South)	0.07	0.20	0.27
Spain (Basque Country, Valencia Region)	0.17	0.36	0.53
Germany (Saxony Anhalt)	0.66	0.30	0.96
Austria (Styria)	0.54	0.37	0.90
UK (Thames Valley, SW England, Wessex)	0.69	0.41	1.10
EUROCAT total	**0.44**	**0.36**	**0.81**

*Perinatal mortality is sum of previous 2 columns. All figures rounded to 2 decimal places.

Figure 8.1 Total prevalence rates per 1000 births (including live births, fetal deaths, and TOPFAs) for spina bifida, cleft lip (with or without palate), and Down syndrome (2006-2010)

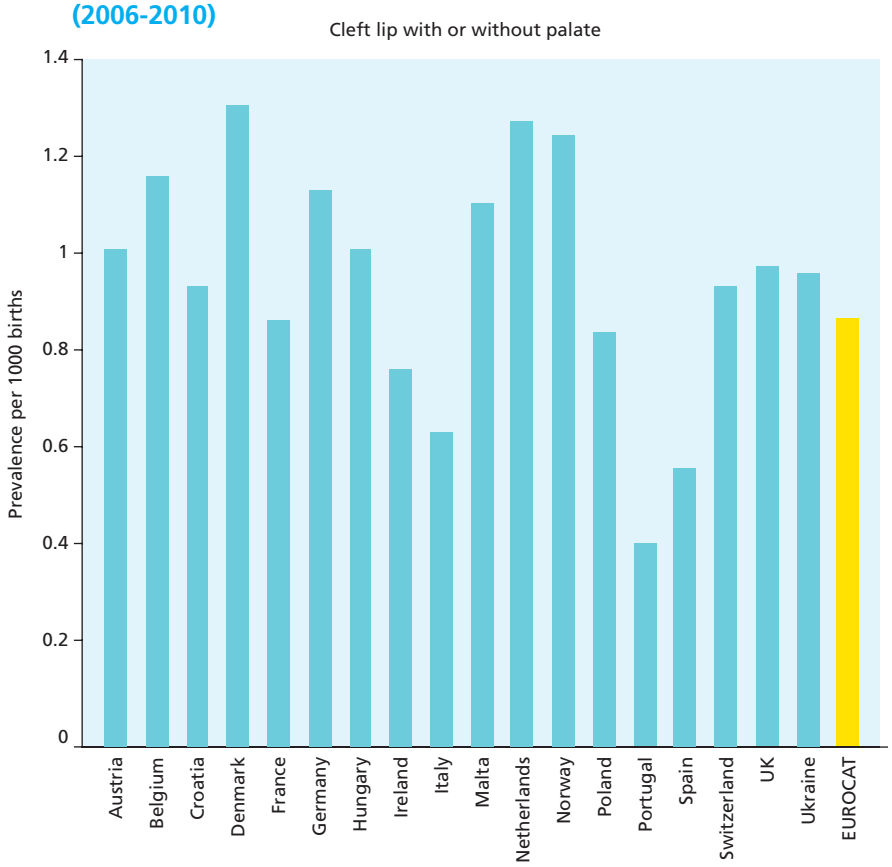
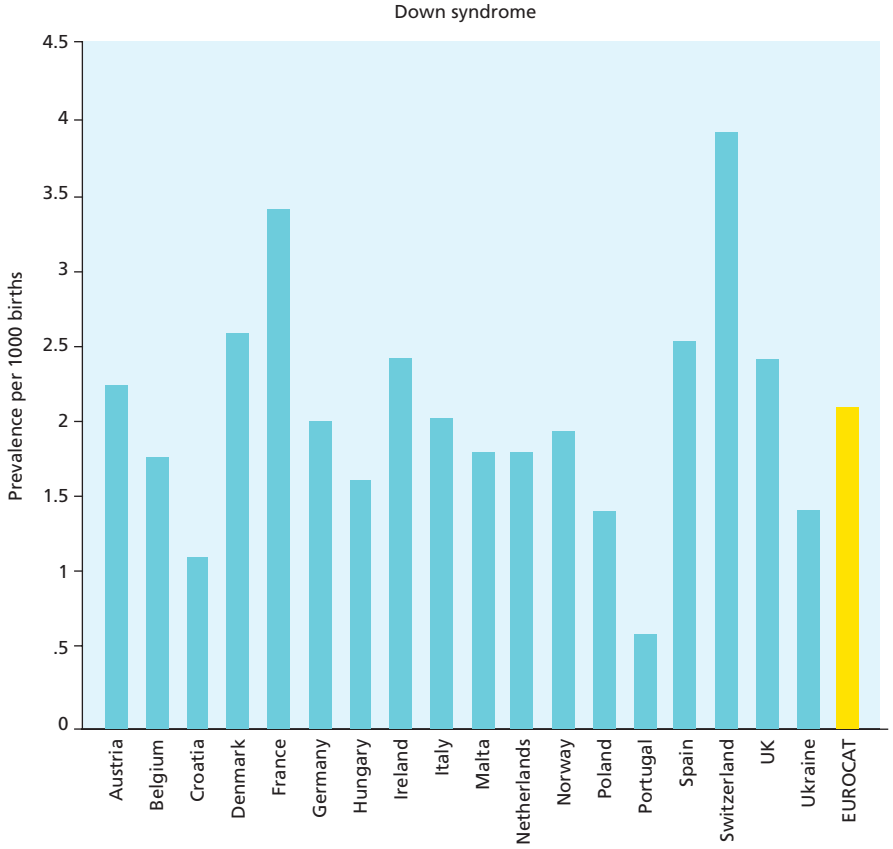
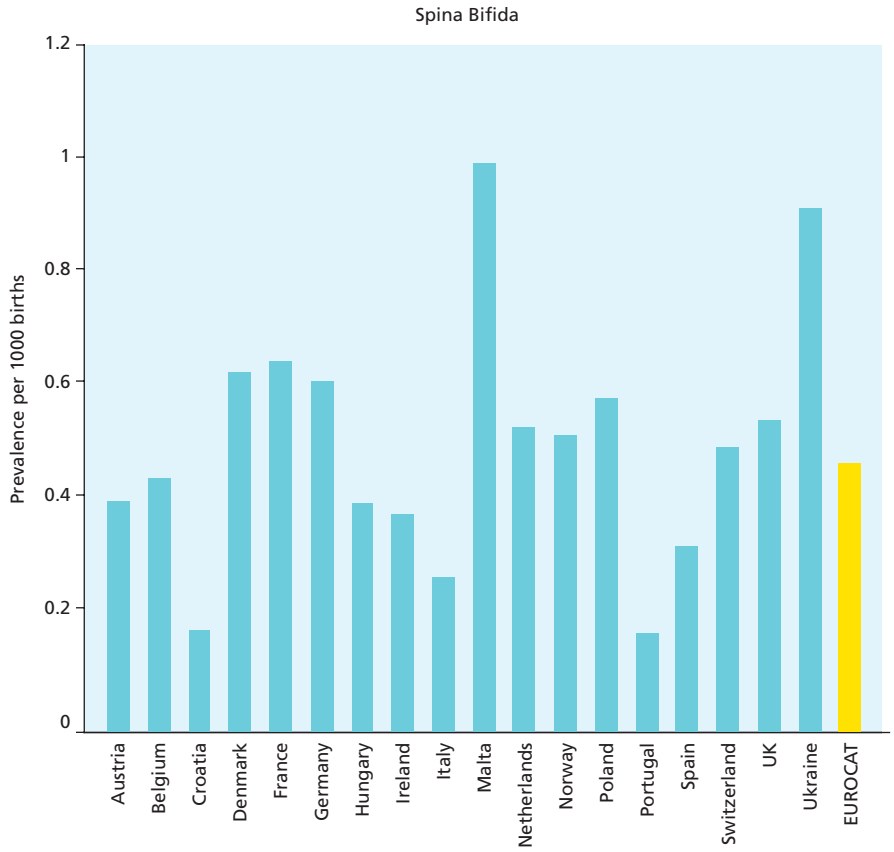


Figure 8.1 (continued)





8.2 SCPE: PREVALENCE OF CEREBRAL PALSY (R4)

Cerebral palsy (CP) has been a recommended PERISTAT indicator for long-term child health outcomes (R4) since 2007, especially as mortality rates can no longer reflect standards in perinatal care accurately in view of the improved survival rates.

CP is the most common motor impairment in childhood. Affecting one child in 500, it is responsible for permanent lifelong activity limitations and participation restrictions. It is often considered to be a group of disorders or clinical descriptions rather than a diagnosis in itself. Since its founding in 1998, the main aim of the Surveillance of Cerebral Palsy (SCPE) network has been to develop a central database of children with CP to monitor trends in birth weight-specific groups,1 to provide data for service planning, and to provide a framework for collaborative research (eg, the SCPE-NET project).

1 HOW DOES SCPE WORK?

1.1 CP DESCRIPTION AND DATA COLLECTION

Criteria for cerebral palsies

Before 1998, the criteria for the different CP subtypes varied through Europe, between countries and between registers. Assessment of the severity of CP in terms of motor and associated impairments also varied. The SCPE network's first important achievement was to establish a consensus on standards, definitions, and classification systems for children with CP. The inclusion criteria and classification of subtypes are available on the SCPE website (www.scpenetwork.eu/) as decision and classification trees. An important follow-up was the development of the Reference and Training Manual (RTM), initially a CD with interactive video illustrations of typical cases, now accessible on the SCPE website. These SCPE standards and criteria have been implemented in a number of European countries, and even on other continents. They have been widely accepted by clinicians as well as scientists and are referenced in a number of recent studies.

Data collection on children with cerebral palsies

The registries acquire their data from different sources, partly due to differences in healthcare organisation. Whereas some registries use questionnaires and forms to be completed by paediatric departments or rehabilitation registries, others have direct access to the patients' health records. SCPE registries put a great effort into ascertainment of cases, using various sources such as summary data from national public health sources, hospital statistics, and health insurance data. Such sources also vary between countries.

CP surveillance requires that the motor deficiency for each child be described in a consistent manner, with specific scales to record motor impairment and associated deficiencies, eg, measurement of the intelligence quotient. The SCPE network has developed a specific data collection form for children with CP.

Data collection of denominators

Finally, the SCPE has worked intensively to acquire accurate background information (ie, denominators). For many countries, these data come from national birth data systems. Routinely collected data on child health present many difficulties, however. One of the most important challenges is that systems usually are not standardised. Data stored for each child in each health

system vary, not only by type, but also in quality. A comparison of cases of CP identified by the Northern Ireland Cerebral Palsy Register with those on the Child Health Computing System found that only 50% of cases were recorded in both systems. Assessment of health at the age of 2 years, for example, is likely to underestimate the prevalence of disability in the population, regardless of whether it uses data from follow-up studies or routinely collected data.

1.2 DATA QUALITY CONTROLS

Feedback to registries

Several measures were established to improve data quality. Firstly, we described all existing tools devoted to data quality. Secondly we requested reports based on information from each 'old' register as well as the new ones. The report contained comprehensive information about the functioning of the register and the data collected. Thirdly, we decided to set up a system of feedback to the registries after each data submission wave. The aim of the feedback is to provide to each registry a summary of the data it submitted, compared with the data submitted by the other registries. During the 2011 annual meeting, we proposed data quality indicators for all registers. These quality indicators were percentages of missing values for 5 core variables (CP type, gross and fine motor function, intellectual impairment, and neuroimaging) and the number of missing values for all the variables in the database. Thanks to this feedback, each registry is more aware now about its own data quality and is able to compare it with the other registries.

Reliability of the SCPE inclusion and classification process[2]

The registration of children with CP is a process that begins with paediatricians examining the child and ends with data managers from the registries. Consequently, we conducted 2 different evaluations. The first focused on agreement between clinicians, based on primary observations, and the second on agreement based on data abstracted from medical records. Overall agreement was rather good for classifying children with CP in different subtypes. Another important finding was that non-physicians knew their limitations and quite often felt that they were not able to decide about inclusion or classification.

Our results indicate that CP is best diagnosed on clinical grounds — a clinician should see the child to assess the neurological signs and assign them to a CP subtype. The use of classification systems, such as that presented in the SCPE Reference and Training Manual, provides a systematic approach to the clinical description of children with CP. Reliability was higher than in previous studies, probably because of the training of professionals in the use of the SCPE classification system. Reliability tended to be higher for clinicians seeing videos. It also appeared that it was sometimes difficult to differentiate between bilateral spastic CP and dyskinetic CP, especially when extracting data from medical records. Ideally, therefore, the clinician seeing and examining the child should: (1) make the decision about CP classification, and then (2) write it clearly in the medical records and, in particular, specify the predominant type for a child with a mixed form of CP. To improve written communication with families and for those abstracting data for CP registers, clinicians should avoid ambiguous or unreliable clinical descriptions.

2 WHAT DATA AND ANALYSIS DOES SCPE PRODUCE?

2.1 NEW DATA

The SCPE common database added more than 3500 children with CP born in 1999-2003. A total of 17 registries submitted data for at least one birth-year cohort. There were 5 new registries

(Iceland, Austria, Latvia, Hungary, and Croatia). Two of them also submitted data on children with CP born in 1990-1998 (Austria and Iceland).

During the second and third waves, the 17 registries submitted data on denominators for birth years 2001-2003, through an Excel file containing 14 sheets. Many also updated denominator data for previous birth years.

Table 8.7 21 European registries submitting data to the SCPE Common Database for 1990-1998 and 1999-2003 periods – Number of children with CP

"Registry	Registry name	Previous data: 1990-1998 birth-year cohorts	New data submitted for 1999-2003 birth-year cohorts	'n' of these new data	Comments
AU-CCPT	Children with Cerebral Palsy in Tyrol	83	1999-2003	47	
DK - DCPR	Danish cerebral palsy register	649	1999-2003	661	extended nationwide
FR - RHE31	Childhood disabilities register of the Haute-Garonne	158	1999-2003	124	
FR - RHEOP	Register for childhood disabilities and perinatal survey	230	1999-2003	197	extended to 2 other counties
HR-CCPR	Croatian Cerebral Palsy Register		2003	19	
HU-HCPS	Pecs Cerebral Palsy Register		1999-2003	96	
IE - EICPR	Eastern Area CP Study	333	1999-2003	211	
IE - SICPR	Southern Ireland CP register	128	no data provided	no data provided	nationwide register planned
IE - WICPR	Western Ireland CP register	98			
IS-ICPR	Iceland CP register	86	1999-2003	46	
IT - CICPR	Central Italy CP register	55	no data provided	no data provided	
IT - CPSNI	Cerebral Palsy Survey of North Italy	61			
LV-RC	Mes esam lidzas rehabilitation center		2000-2003	46	
NO – CPRN	The Cerebral Palsy Register of Norway	201	1999-2002	378	extended nationwide
PT-LCPS	Programa Vigilância Nacional da Paralisia Cerebral aos 5 anos	115 (1996-1997)	2001-2003	492	extended nationwide
SE - GCPR	CP register of western Sweden	377	1999-2003	219	
SL-SCPS	Slovenian Register for CP		1999-2003	195	
SP - DIMAS	Madrid Cerebral Palsy Register	80 (1991-1998)	1999	13	
UK - 4Child	Four Counties database of CPO, vision loss and hearing loss in children	543	1999-2003	201	register closed in 2011
UK - NECCPS	North of England Collaborative Cerebral Palsy Survey	731	1999-2003	305	
UK - NICPR	Northern Ireland Cerebral Palsy Register	490	1999-2003	255	

2.2 NEW ITEMS

New items were added to the common database, providing

i) more information when multiple congenital anomalies co-exist,

ii) age at onset for epilepsy as a proxy for severity, and

iii) neuroimaging classification with 6 different groups for MRI and neonatal ultrasound results.

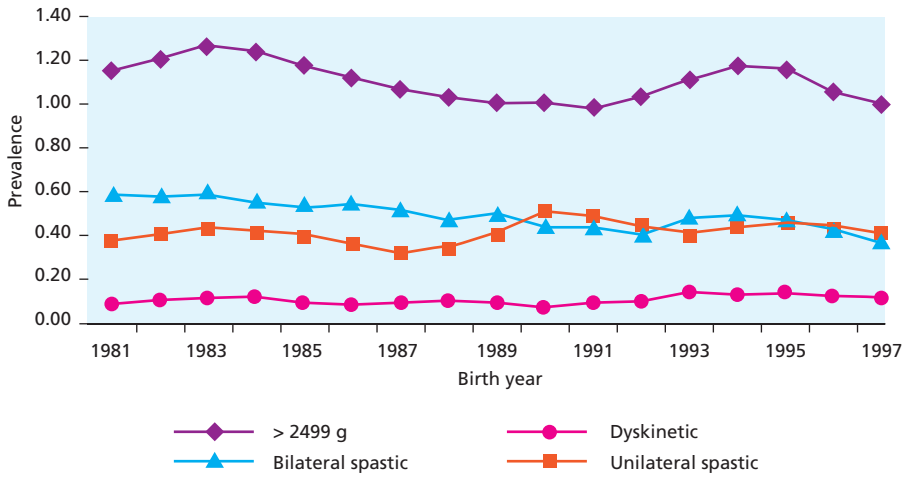
Availability of data and ease of its collection for these items will be checked in the years to come. Further candidates are a communication scale (speech performance) and classification of the mothers' education level.

2.3 TRENDS OVER TIME IN PREVALENCE OF CEREBRAL PALSY

Analysis of the trends in CP prevalence in children with a birth weight ≥ 2500 g or at term[3]

The prevalence of CP did not change much between 1980 and 1998. For every 1000 children born with a birth weight in the typical range, one was likely to have CP. However, the rate of children with a bilateral spastic form decreased from 0.58 in 1980 to 0.33 per 1000 live births in 1998. The rate of children with a unilateral spastic form increased from 0.37 to 0.46 per 1000 live births. During the same period, mortality, ie, the rate of deaths of children with a birth weight in the typical range, decreased by nearly half (from 1.7 to 0.9 per 1000 live births), and the rate of children with a moderate (children either unable to walk or with an intellectual quotient below 50) or severe form of CP (children unable to walk and with an intellectual quotient below 50) decreased slightly.

Figure 8.2 Prevalence of cerebral palsy (3-year moving average), in children of normal birth weight from 15 European registers, 1980-1998.*



* Sellier et al. 2010, Eur J Epidemiol[3]

What does this tell us?
This work tells us that the CP rate was stable among children with a birth weight in the typical range between 1980 and 1998. This may seem disappointing at first glance. Nonetheless, mortality (the number of children who died) decreased quite substantially among children with a birth weight in the typical range, a reflection of progress in neonatal care. Although it is difficult to determine why the rate of bilateral spastic CP decreased and the rate of unilateral spastic CP increased, one plausible hypothesis is that progress in neonatal care led to a reduction in the number of more severe cases.

Further work
We need to follow the trends in CP rates in this population, including by CP subtype (ie, bilateral spastic predominant, unilateral spastic predominant, dyskinetic predominant, or ataxic). Another study showed a decrease in the number of children with CP with very low birth weights.[4] This finding reflects some progress in neonatal care, but especially progress in preventing CP in children with very low birth weights. We also need to improve our understanding of the reasons for the changes in prevalence by CP subtype.

Analysis of the trends in prevalence of children with cerebral palsy with a birth weight between 1500 and 2499 g or a gestational age between 32 and 36 weeks[5]
We used the SCPE database to obtain data on 1164 children with CP born at 32-36 weeks of gestation and on 2159 children with CP and a birth weight from 1500 to 2500 g. These data come from 19 CP registers in Europe and concern children born between 1980 and 1998.

What were the findings?
We found that the proportion of children born between gestational weeks 32-36 who developed CP decreased by approximately 3 per 100 in each year of the study period. This decrease was mainly found among children with the bilateral spastic CP subtype (the subtype considered the form of CP most typically associated with preterm birth). However, we did not find a corresponding decrease in occurrence among children with a birth weight between 1500-2499 g, although fewer children were diagnosed with the most severe CP subtypes.

What does this tell us?
The results show that the observed improvement in survival in these high-risk groups of children during the last 2 decades of the last century has not resulted in an increase in the occurrence of CP. In fact, our results suggest that it may have led to a slight, but significant, reduction in the prevalence of children with CP among those born moderately preterm.

Analysis of trends in children with cerebral palsies of post-neonatal origin[6]
We also sought to analyse trends over time in the prevalence of CP of post-neonatal origin, to investigate the changes in prevalence and severity and to describe the disability profile by aetiology.

What were the findings?
Over the 1976-1998 study period, 404 children were identified with CP of post-neonatal origin (5.5% of the total children registered). The mean prevalence was 1.20 per 10 000 live births, with a significant downward trend ($p=0.001$) and an accentuated decrease in the 1990s. The prevalence of severe cases, which account for around one third of all cases, also decreased significantly over time ($p<0.001$). The prevalence of infectious causes has also decreased significantly since 1989, but no significant decrease occurred for cases due to a vascular episode or of traumatic origin.

What does this tell us?
These results emphasise the need for large population-based surveillance systems for reliable monitoring of trends in prevalence in rare subgroups of children, such as those with acquired CP. The decrease in the overall prevalence as well as in the rate of the most severe cases may be due in part to public health actions targeted specifically at preventing these events.

3 SCPE-NET: COLLABORATION WITH CLINICAL NETWORKS

3.1 AIMS AND OBJECTIVES

The SCPE-NET project (2009-2012), funded by the EU Second Health Programme (DG SANCO), aimed to improve the health and wellbeing of children and young people with cerebral palsies in 2 primary ways: by developing guidance on best practices for the care of children and young people with CP for use by both health professionals and lay carers (eg, parents) and by improving the collection, recording, description, and use of clinical and epidemiological data.
In addition, the project explored the feasibility of applying across Europe the knowledge and experience gained from this work to other childhood impairments and chronic conditions, such as intellectual impairment.

Specific objectives of SCPE-NET project were:
- to disseminate information and best practices for children and young people with CP to parents and professionals;
- to document variations in healthcare provision and access and in outcomes in children and young people with CP;
- to make recommendations for monitoring CP and intellectual impairment at regional or national levels.

3.2 ACHIEVEMENTS

The newly developed classification (neuroimaging findings) and scale (speech performance) add to the already available SCPE tools used worldwide. They facilitate communication between professionals and families. Persons with CP and their families, carers, and professionals may benefit from using the common language elements developed in the project for the purpose of describing children and young people with CP.

The project produced quantitative evidence about variations in a series of clinical interventions and outcomes across Europe (relations between hip luxation rates and preventive programmes, use of intrathecal baclofen, rate and age at gastrostomy tube feeding,[7] and assessment of nutritional status[7]). The demonstration studies included analyses by socioeconomic status, based on the limited data available. A protocol for obtaining good-quality and comparable socioeconomic status data in the EU CP registers is under consideration.

The project succeeded in increasing the SCPE common database by adding 3500 children with CP. Five new registers provided cases and denominators. New items were included in protocols for the registration and data quality assurance procedures, which were further developed and enhanced. Innovative data analysis methods have been incorporated, and new epidemiologic data published. The experience obtained in monitoring CP was applied in drafting recommendations for monitoring severe intellectual disabilities in children and young people.

The SCPE open-access and multilingual website developed by SCPE-NET is an effective platform for disseminating epidemiological information on CP and innovative medical education materials, such as the SCPE Reference and Training Manual. The website includes lay summaries of most reports produced by the project. It contributes to the sustainability of the network by providing access to SCPE publications and reports to all persons and groups interested in children and young people with the cerebral palsies.

3.3 WEBSITE: WWW.SCPENETWORK.EU/

A literature review and 2 online surveys have confirmed that the number of individuals and professionals seeking health-related information on the internet is growing in Europe, although large differences exist between countries. The review identified clear recommendations for providing accessible, up-to-date, and accurate information that is understandable and readable. Surveys in which individuals with CP, their parents, and professionals participated tested these recommendations and identified further information needs. A set of priorities was established to enable the website to become a reference platform for information on the epidemiology of CP: inclusion of lay summaries and graphs; information by type and severity of CP; participation of a user group in the development of the material; and delivery in languages relevant to the target users.

The Reference and Training Manual is the main SCPE tool for disseminating good practices in the CP field. During the past 4 years, existing content has been updated by the authors and new content added. Video sequences and images are available for all types of neurological and neuroimaging findings. This main SCPE information repository is already available online in 3 languages (English, German, and Portuguese) and more will be available soon (Swedish, Latvian, French, Slovenian, Italian, and Spanish).

4 CONCLUSION

The recent SCPE-NET collaborative project took advantage of a unique surveillance network of population-based registers and surveys of **children and young people with the cerebral palsies.**[8] The work plan of the project required close collaboration between registries and their clinical networks, which provided a unique, productive platform for work of high quality and quantity. This collaboration **is in line with the Health Programme's priorities**, including the facilitation of access to medical expertise and information, the validation of best practices in as many member states as possible, and the prevention and reduction of complications of chronic diseases and impairments.

The cerebral palsies are rare conditions. A European network of CP registries permits the study of trends over time in subgroups of children and young people that represent very small numbers in individual registers; these studies would not be feasible otherwise.

The public health interest of registers as useful tools for monitoring chronic conditions has been proved in several domains. However, **running a register requires continued effort and funding.** The participation of registries in a European network represents a great opportunity for enhancing data quality and for taking part in public health and research studies; this participation may also affect their own funding.

The sustainability of the network requires that funding of the registers be reinforced at the level of regions or member states and that the collaborative work — the common database and website — be supported at the EU level. The SCPE network is now in position to intensify its collaboration with international teams in this field.

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