

Prevalence and characteristics of children with cerebral palsy in Europe

Surveillance of Cerebral Palsy in Europe (SCPE)
(For participating centres see Appendix I)

Correspondence to Ann Johnson, National Perinatal Epidemiology Unit, Institute of Health Sciences, Old Road, Oxford, OX3 7LF, UK
E-mail: ann.johnson@perinat.ox.ac.uk

Following agreement on definitions and classification, a central database was set up to include information on over 6000 children with cerebral palsy (CP) from 13 geographically defined populations in Europe. The overall rate for the period 1980 to 1990 was 2.08/1000 live births (95% CI 2.02 to 2.14). One in five children with CP (20.2%) was found to have a severe intellectual deficit and was unable to walk. Among babies born weighing less than 1500g, the rate of CP was more than 70 times higher compared with those weighing 2500g or more at birth. The rate of CP rose during the 1970s, but remained constant during the late 1980s. Future analyses will include data from children born in the 1990s. This collaborative work provides a powerful means of monitoring trends in birthweight-specific rates of CP and an infrastructure for research and service planning.

In 1998, a collaborative network of cerebral palsy (CP) registers and surveys in 14 centres in eight countries across Europe was formed. The aim of the network (called Surveillance of Cerebral Palsy in Europe; SCPE) was to develop a central database of children with CP in order to monitor trends in birthweight-specific rates, to provide information for service planning, and to provide a framework for collaborative research.

It was recognized that the centres included in the network, all of which were able to include children from a geographically defined population, had previously reported differing prevalence rates (from 1.5/1000 live births to 3/1000 live births). The extent to which these reflected differences in case definition, inclusion and exclusion criteria, and classification systems was uncertain. These terms were reviewed and a consensus reached. The agreed criteria for case definition and inclusion and exclusion have been reported previously (SCPE 2000). A standard perinatal minimum dataset was also agreed.

In this paper we report the overall and birthweight-specific prevalence rates of CP in 13 of the 14 centres in the network. We examine changes during the late 1970s and 1980s in these rates. These are important baseline data against which CP prevalence rates in the 1990s, a time of considerable change in obstetric and neonatal care, can be compared.

Method

By June 1999, 13 of the 14 centres were able to send anonymous data on children with CP to a coordinating centre in Grenoble, France. The birth years included were 1976 to 1990. Children who were at least 4 years of age at the time of registration were included. In addition, children who had died between the ages of 2 and 4 years and had clear signs of CP were also included on the database. Children who sustained brain damage resulting in CP after the neonatal period (28 days after birth) were included in the database but excluded from all analyses as well as prevalence rates in this report: they will form the basis of a separate paper. Children born to mothers living in the areas under study at the time of delivery and those who had moved into the area were eligible for inclusion in the database. The proportion of children within these categories varied between centres according to the data collection policy of each centre. In this paper, only the population born to mothers resident in the area of study at the time of delivery were included. There is one exception to this: because of considerable loss due to migration from the population of children born to mothers resident at the time of delivery in centre 1, the population 'currently resident in the area' was used instead.

There were 45 variables in the common dataset including birthweight, gestational age, multiple or singleton birth, maternal age, parity, a description of the motor impairment, level of function, associated sensory and intellectual impairment, and severity of disability.

Data were sent without personal identifiers (name and address), and date of birth was limited to month and year of birth to conserve anonymity. Identifying numbers used by each centre were retained to allow data checking. In addition, information on the population from which the children with CP were identified was sent to the coordinating centre, including the number of live births and neonatal deaths by year, by birthweight group, by sex, and by gestational age. Not all of these variables were available from routine sources for every centre.

At the central coordinating centre, case histories were checked to ensure that the agreed definition and classification system was used. Translation rules had been developed specifically for each centre and data were submitted to integrity constraints (routine checks to ensure values were 'sensible') and internal validation before entering new data onto the common database. There were numerous exchanges between the coordinating centre and SCPE collaborators and a number of errors were detected and corrected. This procedure was also very helpful to collaborators in standardizing data on their own registers.

STATISTICAL METHODS

Prevalence rates are presented with binomial exact 95% confidence intervals. Logistic modelling was used to analyze differences in rates between centres and trends over time. A threshold of 0.005 was used in this modelling.

Results

From 13 of 14 centres, a total of 6502 children born between 1976 and 1990 were entered onto the database. Of these, 357 children had CP of postneonatal origin. Data on postneonatal cases were available from only eight of the 13 centres; based on these eight centres, the proportion of children whose CP was of postneonatal origin was 7.8%. These 357 children were excluded from analyses in this paper. The centres and their identifying numbers are listed in Appendix I.

The numbers of children and the birth years covered by the registers or surveys varied widely from centre to centre (Table I). Four centres (2,10,13, and 14) had conducted a cross-sectional survey; two of these (centres 2 and 13) have continued to collect data and are now compiling registers. Ten of the centres held ongoing CP registers. Centre 10 had collected information only on children with bilateral spastic CP and data were excluded from analyses when indicated.

All centres reported more males than females; overall the

M:F ratio was 1.33:1. The proportion of all children with CP who had died varied between centres from 0 to 6.6%, reflecting differences in ascertainment methods.

Over 90% (5689) of children on the database were born to mothers resident in the area of study at the time of delivery. The remainder of the paper is concerned with the population born to mothers resident in the area of study at the time of delivery except for centre 1 where the population currently resident in the area was used instead.

CP SUBTYPES

Excluding those children from centre 10, the distribution of CP subtypes is shown in Table II. Of the 4792 children born in this time period, 85.7% (95% CI 84.8 to 86.7) were considered to have spasticity, 6.5% (95% CI 5.8 to 7.2) dyskinesia, 4.3% (95% CI 3.8 to 4.9) ataxia, and in the remaining 3.7% the CP type was unknown.

The most common subtype in this dataset was bilateral spastic CP. Overall, 54.9% (95% CI 53.5 to 56.4) of all children with CP had this subtype. The overall rate/1000 live births of bilateral spastic CP was 1.16, and varied from 0.62 in centre 4 to 1.75 in centre 12.

Just over a quarter of all the children with CP (29.2%; 95% CI 27.9 to 30.4) had unilateral spastic CP (hemiplegia). The rate/1000 live births of hemiplegia was 0.6. The lowest rate reported was 0.27 from centre 13 and the highest was 0.82 reported from centre 11.

The 310 children with a predominantly dyskinetic presentation contributed only 6.5% of cases. The overall rate/1000 live births was 0.14 and varied from 0.03 in centre 11 to 0.3 in centre 12. Similarly there was a wide variation in the proportion of children with ataxia. Only 4.3% (95% CI 3.8 to 4.9) of the children in this dataset had ataxic CP and the rate/1000 live births varied from 0.03 in centres 5, 8, and 12 to 0.14 in centre 9.

The remaining 177 (3.7%) children with CP were not classified into a subtype group. Over a fifth of these 177 children

Table I: Number and characteristics of children with CP reported from each centre in the European Network

Centre nr	Number of children with CP	M:F ratio	Number (%) of children with CP known to have died	Number (%) born to residents of area ^c	Number (%) resident in the area ^d	Birth years
1	261	1.46	7 (2.7)	196 (75.1)	261 (100)	1980–1989
2	253	1.39	4 (1.6)	159 (62.9)	253 (100)	1976–1985
3	783	1.24	50 (6.4)	731 (93.4)	781 (99.7)	1984–1990
4	232	1.37	8 (3.5)	232 (100)	232 (100)	1976–1990
5	653	1.19	40 (6.1)	616 (94.3)	645 (98.8)	1981–1990
6	649	1.25	7 (1.1)	624 (96.2)	649 (100)	1976–1990
8	272	1.47	18 (6.6)	272 (100)	261 (96)	1976–1990
9	668	1.32	35 (5.2)	550 (82.3)	611 (91.5)	1984–1990
10 ^a	220	1.6	5 (2.3)	220 (100)	–	1976–1986
11	919	1.3	10 (1.1)	919 (100)	881 (95.9)	1976–1989
12	1044	1.48	45 (4.3)	1010 (96.7)	892 (85.4)	1976–1990
13	67	1.16	0 (0)	61 (91)	65 (97)	1977–1990
14	124	1.58	0 (0)	99 (79.8)	124 (100)	1977–1988
Total ^b	6145	1.33	224 (3.8)	5689 (92.6)	5655 (92)	

^aOnly children with bilateral spastic CP. ^bTotals (and %) exclude centre 10. ^cChildren born to mothers living in area at time of delivery. ^dChildren resident in area at time of registration.

had died between 2 and 5 years of age. Subtype tends to change over time and there may have been uncertainty about classifying a child with CP who died in the early years. Centres in which all case histories were successfully classified, included both registers and surveys.

BIRTH COHORT PREVALENCE OF CP BY CENTRE

Excluding centre 10, and centre 14 (from which denominator data were not available at the time), the overall birth cohort prevalence rate for CP among children born to residents in the areas studied, in the 11-year period 1980 to 1990 was 2.08/1000 live births (95% CI 2.02 to 2.14). Five centres had rates which fell outside the 95% confidence limits for the overall rate. Four centres (centres 1, 2, 3, and 4) had lower rates than the other centres and one centre (12) had a higher rate (Fig. 1).

One explanation of the variation in prevalence rate between centres is the difference in severity threshold for including children as having CP. If the more mildly affected children are excluded from a centre, the prevalence rate will be lower than in a centre where they are included. In a centre where those with milder forms of CP are excluded, the proportion of children with CP who are non-walkers (a marker of severity) will be higher. Figure 2 shows the proportion of non-walkers by centre with the CP birth cohort prevalence rate for each centre. Overall, a third (30.7%) of children with CP were not walking. Two of the four centres (centres 1 and 2) with low birth-cohort prevalence rates had the highest proportions of non-walkers.

CP AND ASSOCIATED IMPAIRMENTS

Severity of the level of impairment and disability among children with CP was also determined by the presence of additional intellectual or sensory impairments or seizures. Complete data on these were not available from all centres. Among the population of children with CP born to mothers resident in the areas being studied (excluding centre 10 and centre 3 which had no information on intellectual impairment), 31% (1150 of 3708) had severe intellectual deficit (Table III). The

rate of CP with severe intellectual impairment/1000 live births was 0.61. Over one in 10 children (11.1%: 533 of 4792) had severe visual impairment. From centres where data on

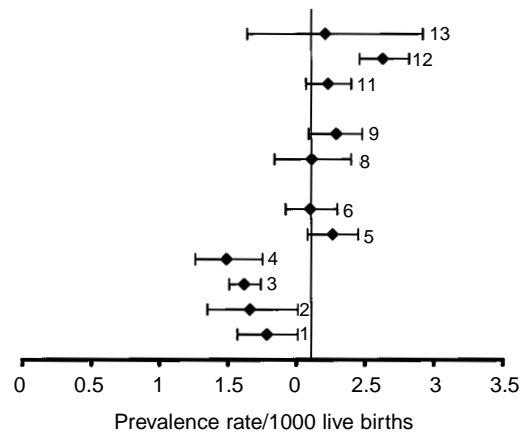


Figure 1: CP prevalence rate per 1000 live births in each centre, 1980-1990.

	Prevalence rate	95% confidence limits	
13 Viterbo province (IT)	2.21	1.64	2.92
12 East Denmark (DK)	2.63	2.46	2.82
11 Mersey region (UK)	2.23	2.07	2.4
9 Oxford region (UK)	2.29	2.09	2.48
8 Northern England (UK)	2.11	1.84	2.4
6 Göteborg region (SW)	2.1	1.92	2.3
5 Northern Ireland (UK)	2.26	2.08	2.45
4 Cork and Kerry (IE)	1.49	1.26	1.75
3 Scotland (UK)	1.62	1.51	1.74
2 Haute Garonne (FR)	1.66	1.35	2.01
1 Iserre County (FR)	1.78	1.57	2.01
Mean overall rate	2.08	2.02	2.14

Table II: CP subtypes by centre for birth years 1980 to 1990

Centre nr	Spastic						Dyskinetic		Ataxic		Unclassified		Total n
	Unilateral		Bilateral		Unknown		n	%	n	%	n	%	
	n	%	n	%	n	%							
1	70	(26.8)	121	(46.4)	3	(1.1)	8	(3.1)	18	(6.9)	41	(15.7)	261
2	14	(13.7)	51	(48.6)	3	(2.9)	8	(7.8)	7	(6.9)	19	(18.6)	102
3	183	(24.9)	362	(49)	0	(0)	94	(12.8)	44	(6)	53	(7.2)	736
4	61	(40.4)	63	(41.7)	0	(0)	16	(10.6)	11	(7.3)	0	(0)	151
5	216	(35.1)	332	(54.7)	1	(0.2)	19	(3.1)	7	(1.1)	41	(6.7)	616
6	163	(34.5)	264	(56.4)	0	(0)	21	(4.4)	25	(5.3)	0	(0)	473
8	76	(34.2)	127	(56.3)	5	(2.3)	11	(5)	3	(1.4)	0	(0)	222
9	157	(28.5)	268	(50.1)	51	(9.3)	25	(4.5)	33	(6)	16	(2.9)	550
10	0	(0)	149	(100)	0	(0)	0	(0)	0	(0)	0	(0)	149
11	266	(36.8)	413	(50.2)	0	(0)	10	(1.4)	34	(4.7)	0	(0)	723
12	152	(18.5)	547	(66.5)	16	(1.9)	94	(11.4)	10	(1.2)	4	(0.5)	823
13	6	(12)	38	(75.5)	0	(0)	4	(8)	2	(4)	0	(0)	50
14	33	(38.8)	47	(53.3)	0	(0)	0	(0)	2	(2.4)	3	(3.5)	85
Total ^a	1397	(29.2)	2633	(54.9)	79	(1.6)	310	(6.5)	196	(4.3)	177	(3.7)	4792

^aTotals (and %) exclude centre 10.

seizures were available, 20.7% of participants (470 of 2275) were reported to have active seizures. The most severely affected children tended to be those with severe intellectual impairment and who were not walking. One in five children with CP had this level of severity (20.2%; 95% CI 18.9 to 21.4). The frequency of associated impairments among children with bilateral spastic CP reported by centre 10 did not differ from the frequency for all children with CP.

The prevalence rate of severe CP (excluding centres 3 and 10), that is, children with severe intellectual impairment and who were unable to walk, was 0.42 per 1000 live births (95%CI 0.40 to 0.46). Differences in the rate of severe CP by centre are shown in Figure 3. Rates vary from 0.2/1000 live births (95%CI 0.12 to 0.31) in centre 4 to 0.59/1000 live births (95%CI 0.51 to 0.69) in centre 12. The rates for 7 of the 10 centres with available data differed no more than would be expected by chance.

BIRTHWEIGHT-SPECIFIC RATES OF CP

Data on birthweight-specific rates were available for eight centres for which reliable denominator data were available (Table IV). Birthweight was not known for 42 of 3434 children with CP in these eight centres. Excluding centre 10, the rate of CP/1000 neonatal survivors among babies with known birthweight and who weighed <1500g was 72.6 (95% CI 67.4 to 77.8), among those weighing 1500 to 2499g was 11.1 (95% CI 10.4 to 11.8) and those weighing 2500g and more was 1.2/1000 (95% CI 1.13 to 1.24). There was considerable variation between centres in the rate of CP among very low-birthweight (VLBW: birthweight <1500g) babies. The lowest rate was in centre 3, which also had low rates in the other birthweight strata. Centre 10 which collected only bilateral spastic CP data had a CP rate among low-birthweight babies which was similar to the other centres, but the rate among babies weighing more than 2500g at birth was lower, reflecting the

Table III: Associated impairments among children with CP born 1980 to 1990

Centre nr	Number of children	Severe intellectual deficit ^a		Severe visual impairment ^b		Active seizures		Severe intellectual deficit & not walking	
		%	Rate/1000 live births	%	Rate/1000 live births	%	Rate/1000 live births	%	Rate/1000 live births
1	261	42.8	0.63	7.7	0.14	38.8	0.68	29.9	0.38
2	102	43.6	0.67	8.8	0.15	33.7	0.5	29.8	0.46
3	736	–	–	10.6	0.17	10.4	0.12	–	–
4	151	27.1	0.35	4	0.06	14	0.17	15.6	0.2
5	616	39	0.65	9.9	0.22	–	–	23.4	0.44
6	473	23.9	0.5	14.2	0.3	20.8	0.41	19.3	0.4
8	222	22.4	0.44	5	0.1	22.9	0.37	14.6	0.28
9	550	28.1	0.56	11.3	0.26	20.6	0.46	20.4	0.44
10	149	37.2	0.44	17.5	0.21	25.4	0.29	21.8	0.25
11	723	27	0.59	7.9	0.18	–	–	17.2	0.38
12	823	34.1	0.89	17.1	0.45	–	–	22.7	0.59
13	50	41.7	0.89	26	0.58	37.8	0.75	27.1	0.58
14	85	25	–	9.4	–	10.7	–	12.5	–
Total ^c	4792	31	0.61	11.1	0.23	20.7	0.34	20.2	0.42

^aIQ less than 50. ^bVisual acuity less than 0.3 in better eye after correction or 'blind'. ^cTotals (and %) exclude centre 10.

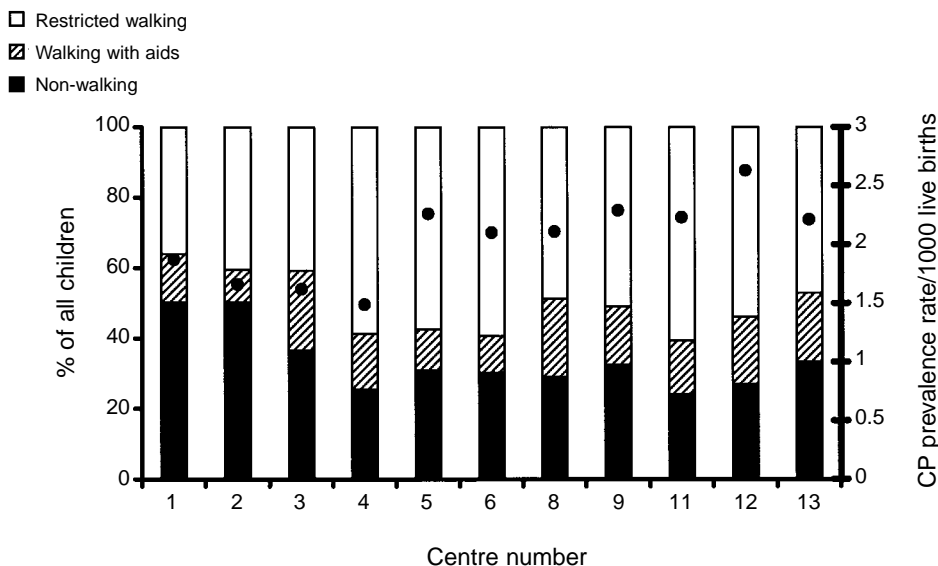


Figure 2: Severity of CP and birth cohort prevalence rates by centre. Solid dots indicate CP prevalence rate/1000 live births in each centre (see right y axis).

association of birthweight and subtype of CP.

The proportion of children with CP within birthweight groups also varied from centre to centre (Fig. 4). Of those with known birthweights, 21.1% (95% CI 19.9 to 22.3), weighed less than 1500g at birth; 26.4% (95% CI 25.1 to 27.7) weighed between 1500 and 2499g, and 52.4% (95% CI 50.9 to 53.8) weighed 2500g and more. The highest proportion of children under 2500g was in centre 10, once again reflecting birthweight-specific differences in CP subtype.

TIME TRENDS IN BIRTH COHORT PREVALENCE RATE OF CP BETWEEN 1976 AND 1989

Based on information from 11 centres (centres 10 and 14 excluded), there has been an upward trend in the overall rate of CP in the 14 year period 1976 to 1989 ($p < 0.001$). This trend was seen in all centres except centre 3, although the increase was not statistically significant in all centres (Fig. 5).

In order to address the concern that the severity of CP may have increased over time, we examined trends in the rate of CP associated with severe intellectual impairment and inability to walk in 10 centres (excluding centres 3, 10, and 14). The overall rate of children with severe CP has increased over the 14-year period ($p < 0.001$). This increase was seen in all centres, though the trend was not statistically significant in all centres (Fig. 5).

It is clear from Figure 5, however, that the change in CP rate over time during the later 1980s differs from the trend seen in the late 1970s and early 1980s. Using data from birth years 1984 to 1989, and excluding centres 3, 10, and 14, there was no trend over time in either the overall rate of CP ($p = 0.44$) or in the rate of severe CP, that is, children with severe intellectual impairment and who were unable to walk ($p = 0.1$). During this later period (1984 to 1989), differences in CP rates across centres were no more than would be expected by chance except for centre 12 which had a significantly higher overall rate of CP than the other eight centres ($p < 0.001$) and also a higher rate of severe CP ($p < 0.001$).

In summary, the upward trend in overall prevalence rate for CP and the rate of the most severely affected children during the late 1970s was followed by a plateau effect in the 1980s. The downward tendency at the end of the 1980s was not statistically significant and further data are needed to clarify whether this is a true and continuing downward trend.

Discussion

Collaborators in SCPE (Surveillance of Cerebral Palsy in Europe) have developed a database which is a powerful tool for monitoring trends in the birthweight-specific rate of CP and in providing a framework for aetiological and health services research. The cases are drawn from a live birth population of 3.3 million and it is the largest database of children with CP in the world.

The database was set up against a background of uncertainty about whether variations in CP prevalence rates reported

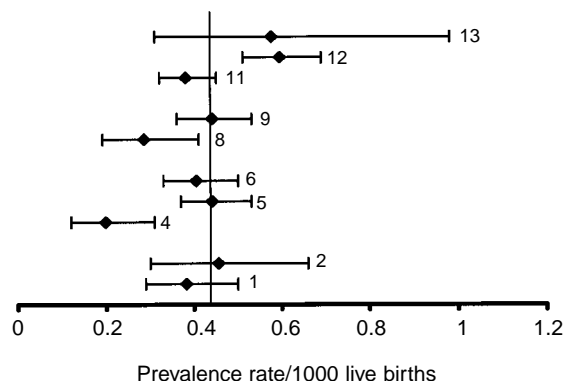


Figure 3: Severe CP^a prevalence rate per 1000 live births in each centre, 1980-1990.

	Prevalence rate	95% confidence limits	
13 Viterbo province (IT)	0.58	0.31	0.98
12 East Denmark (DK)	0.59	0.51	0.69
11 Mersey region (UK)	0.38	0.32	0.45
9 Oxford region (UK)	0.44	0.36	0.53
8 Northern England (UK)	0.28	0.19	0.41
6 Göteborg region (SW)	0.4	0.33	0.5
5 Northern Ireland (UK)	0.44	0.37	0.53
4 Cork and Kerry (IE)	0.2	0.12	0.31
2 Haute Garonne (FR)	0.46	0.3	0.66
1 Isere County (FR)	0.38	0.29	0.5
Mean overall rate	0.43	0.4	0.46

^aSevere CP = IQ < 50 and not walking.

Table IV: Birthweight specific CP prevalence rates in eight centres 1980 to 1990 (Number and rate per 1000 neonatal survivors)

Centre nr and years included	Number of children with CP	Overall CP rate per 1000 neonatal survivors	Birthweight (g)						Number with unknown birthweight
			< 1500		1500-2499		≥ 2500		
			n	Rate	n	Rate	n	Rate	
3 (1985-90)	625	1.61	131	52	188	9	274	0.8	32
4 (1986-90)	70	1.7	10	58	14	10	38	1	8
6 (1980-90)	473	2.11	81	75	107	14	285	1.3	0
8 (1983-90)	170	1.99	36	73	42	9	92	1.3	0
9 (1984-90)	550	2.3	117	75	140	11	293	1.3	0
10 (1980-86)	149	1.22	42	63	53	11	54	0.5	0
11 (1980-89)	723	2.24	143	79	175	11	340	1.3	0
12 (1980-90)	823	2.64	179	91	230	14	412	1.4	2
Total ^a	3434	2.14	697	73	896	11	1734	1.2	42

^aTotals (and %) exclude centre 10.

by centres could be explained by differences in definition and classification. Using agreed and preset guidelines, 11 centres were able to provide data from which overall birth cohort prevalence rates could be derived. Six of the 11 centres showed overall rates which differed no more than would be expected by chance. Further examination of the five centres which showed significantly different rates revealed a number of possible explanations. Four of these five centres had lower overall rates than expected. Centres 1 and 2 had a low overall rate but with a relatively high proportion of severely affected children among their populations. Their rates of severe CP were comparable with other centres. This suggests that the lower rate in these two centres may be part-

ly accounted for by under-ascertainment of the milder cases. Centre 3 had an overall low prevalence rate of CP for the period 1984 to 1990, and showed a sharp fall in prevalence rate during the time when all other centres showed an increase or remained constant. The low rate was present within all birthweight strata suggesting that there might be a low ascertainment level. Further enquiry revealed that procedures for maintaining the register had lapsed during the late 1980s leading to serious under-ascertainment during those years. The fourth centre with a low rate was centre 4, which had both an overall low rate of CP and a lower-than-expected proportion of children with severe functional loss. The proportion of VLBW children with CP was also low. The reason for

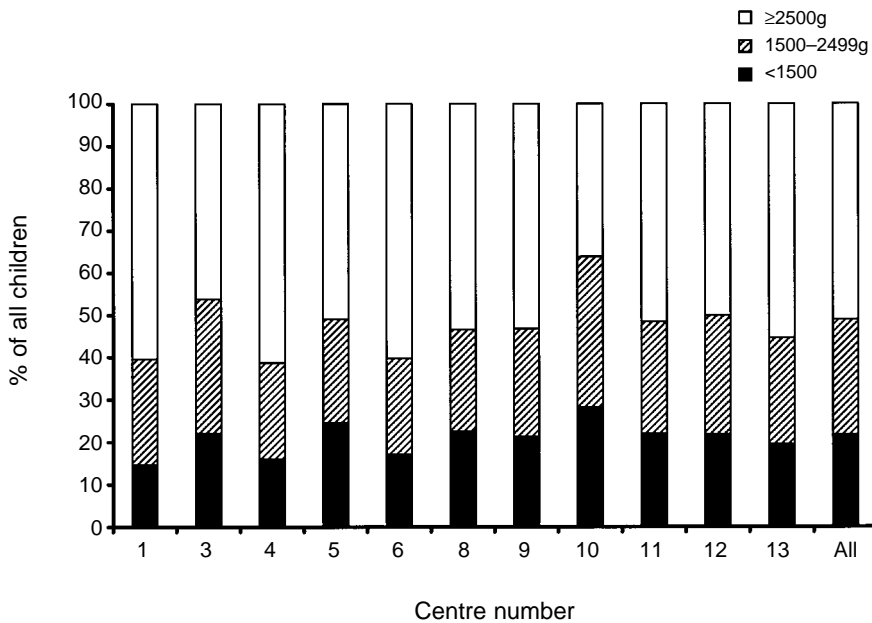


Figure 4: Proportion of CP children by birthweight group by centre.

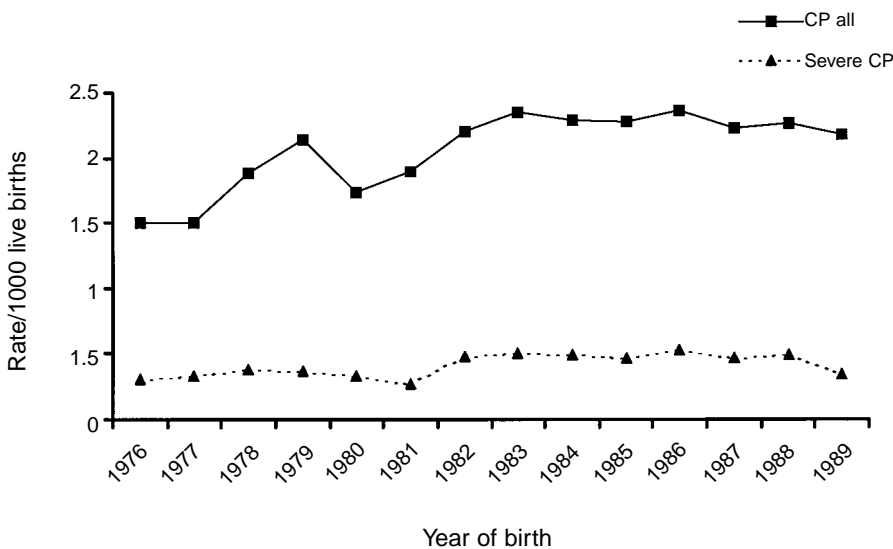


Figure 5: Trends in rate of CP from 1976 to 1989.

this unusual pattern in this centre is not clear. Under-ascertainment may be a factor and it is also possible that high mortality rates among low birthweight babies and patterns of neonatal care may have had an impact on the risk of CP in neonatal survivors. A further possibility is that neonatal survivors with brain injury died in infancy before diagnosis could be made.

In centre 12 there was an unusually high rate of CP, apparent within all the birthweight strata. This has been previously reported by the SCPE team from centre 12 (Topp et al. 1997); and they attributed the high rate partly to a high ascertainment level of mild cases and possibly to a 'high risk' population. The level of risk in a population defined by birthweight may be related to the birthweight distribution. If this is shifted to the right, as has been reported in some Scandinavian countries, and hence babies weighing less than 1500g at birth are relatively immature, the low birthweight CP rates are likely to be higher. The frequency of multiple births in a population may also have an impact on CP rates both overall and within birthweight groups. Among babies born of a multiple pregnancy, the birthweight distribution is shifted to the left, that is, babies weighing less than 1500g are relatively more mature and, therefore, tend to have a lower risk of CP compared with singletons of comparable weight. In more recent years, the CP rate in centre 12 has fallen particularly among babies with a low birthweight. Although in a recent publication this fall has been related to changes in neonatal care in that period (Topp et al. 2001), the interrelationships of birthweight distribution, mortality, the impact of multiple births, and patterns of care on the prevalence of CP need further study in all centres.

One further centre (centre 13) has an atypical distribution of CP subtype and severity. This centre covers a small geographic area and these differences are probably accounted for by small numbers. The area covered by the register is being extended and future rates may be less prone to random variation.

This relatively constant birth cohort prevalence rate of CP across many centres has occurred despite differences in the extent to which children with CP who die are included on a register. As these children tend to be the most severely affected, exclusion of these might underestimate the rate of severe CP overall and within some centres. The proportion of children with CP included on the database who have died is low. Studies in which survival patterns of children with CP have been explored report that over 5% of children with CP die within the first 5 years and a further 5% die between the ages of 5 and 15 years (Hutton et al. 1994). The SCPE collaboration will be addressing the inconsistencies in including children with CP who die. This may not be easy as death certificates rarely list CP as a secondary cause of death and these cases are easily 'missed'.

It appears that ascertainment problems, either overall or of children with milder functional loss, account for most of the variation in overall prevalence rate. Assuring complete ascertainment is a key issue in maintaining registers and difficulties may arise in a number of ways. If there is a high level of early migration out of the area, there is under-ascertainment of the population of children born to mothers resident at the time of birth. On the other hand, provision of centralized services for children with severe disabilities in an area may result in an influx of children with severe disability, hence changing the characteristics of the population of children currently resident

in an area. Late diagnosis, particularly of milder cases of CP, is also a problem when compiling data on the more recent birth years, although it is unlikely to be a major factor in the decline of rates in the late 1980s reported here. A final issue is the criteria for inclusion or exclusion under the umbrella term of CP. Not only will differences in the ways these are currently applied across centres result in spurious differences in rates, but also inclusion criteria will need to be constantly reviewed. For example, some conditions may later prove to be progressive disorders and need to be excluded (Williams and Alberman 1998). We clearly need to continue to explore optimal methods of ascertainment and remain vigilant regarding inclusion and exclusion criteria. Overall, however, we feel that cases from the majority of centres and for recent birth years, particularly if milder cases are excluded, can be combined for study purposes and that it is appropriate to pool such cases for examining trends over time and informing service planning.

There has been interest in studying CP subtypes as it is likely that different phenomenological manifestations of CP may have different aetiologies (Krägeloh-Mann 2000). Indeed, it may be inappropriate to continue to analyze the characteristics of CP populations overall except for the purposes of service planning. CP can no longer be regarded as a single entity but rather a group of conditions. It is important, therefore that any classification system identifies subgroups reliably and appropriately. Although all centres used the same classification system, there were some important differences in the distribution of CP subtypes. This could be due to persisting interobserver variation in applying the classification criteria. For example, there may be differences in the selection of the 'dominant impairment' in children with both spasticity and dyskinesia. Some of the widest variation between centres was in the dyskinetic group. In future work, the SCPE collaboration plans to develop a video training tool which, together with interobserver testing, should further standardize the classification system. There may, however, be true differences in the distribution of CP subtypes which may be related to different birthweight distributions among survivors. In centre 10, which collected information only on bilateral spastic CP, infants weighing less than 2500g are over-represented compared with the other centres, suggesting that this subtype is more common in low-birthweight babies. It is likely, however, that there are other aetiological factors which determine subtype and these will be explored further in a separate paper.

Comorbidity in the form of intellectual or sensory impairment is common in CP and reflects brain injury which extends beyond the motor tracts. Data on these additional impairments was not as complete as the descriptions of the motor impairment, and rates of these may be underestimated. The presence of comorbidity has important implications for planning and providing services. Through the 1970s and 1980s, neonatal mortality, particularly among VLBW babies fell in most European countries and there was a concern that neonatal intensive care had 'rescued' babies with extensive brain injury who would previously have died (Pharoah et al. 1996, Topp et al. 1997). The overall rate of CP and the rate of severe CP did increase sharply in the late 1970s and early 1980s. This has been reported previously and is usually attributed to the increasing number of VLBW survivors during this period (Pharoah 1990, Hagberg 1996). The rate levelled off in the late 1980s and there is evidence from some

centres that the birth cohort prevalence rate of CP among VLBW babies was falling in the early 1990s. This is in spite of the increasing numbers of multiple births, with their risk of preterm birth, and a continuing fall in neonatal mortality rates (Surman et al. 2001, Topp et al. 2001). The extent to which this fall in CP rate is attributable to new therapies which were widely used in the early 1990s, such as antenatal steroids and surfactant, remains to be tested. However, this trend is not reported from all centres. Colver and colleagues (2000) reported a rise in the CP rate in all birthweight groups in the early 1990s and it is now important to monitor the changes in CP rate beyond 1990 in centres across Europe. The SCPE collaborative group plan to continue to build up the database over the next few years.

In recent years interest has focussed on the particular vulnerability to white-matter damage in low-birthweight infants (Paneth 1994). Although there is a 70-fold increase in risk among neonatal survivors who weigh less than 1500g compared with babies weighing 2500g and more, over half the children with CP on the database are in the larger weight group. Considerable advances have been made in understanding the contribution of infection and the inflammatory response in white-matter damage in preterm babies (O'Shea et al 1998, Nelson and Willoughby 2000), and neuroimaging studies have contributed important information about the pathogenesis of CP in both children born preterm and those born at term (de Vries et al. 1993, Krägeloh-Mann et al. 1995). Genetic influences (Pettersen et al. 1990), foetal growth patterns (Blair and Stanley 1990), brain maldevelopment (Evrard et al 1997), and antenatal and intrapartum factors (Gaffney et al. 1994) may all play a part in the causal pathways of CP in term babies. It is not possible to explore these from existing data in the database but there is a potential to develop further work using the database as a sampling frame for case control studies.

Finally, and perhaps most importantly, the database can be used as basis for new studies to measure the impact of functional loss associated with CP on the lives of children and their families. The extent to which services alter the quality of life for the children and their families is not clear. The views of the children themselves and their parents are essential in order to inform those planning and providing services appropriately. We plan to continue to build up the database and use it as an infrastructure for these and other studies. In this way the database will not be simply a register but will make a contribution directly or indirectly to the day to day lives of the thousands of children across Europe with this serious disabling disorder.

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Appendix I: Collaborating centres in SCPE (Surveillance of Cerebral Palsy in Europe)

Centre	Area covered by number survey or register	Country	Participants
1	Iserre County	France	C Cans, P Guillem
2	Haute Garonne	France	C Arnaud, F Baille
3	Scotland	UK	J Chalmers
4	Cork and Kerry counties	Eire	V McManus, G Cussen
5	Northern Ireland	UK	J Parkes, H Dolk
6	Göteborg region	Sweden	B Hagberg, G Hagberg
8	Northern Region	UK	S Jarvis, A Colver
9	Oxford Region	UK	A Johnson, G Surman
10	Tübingen district	Germany	I Krägeloh-Mann, R Michaelis
11	Mersey Region	UK	MJ Platt, P Pharoah
12	East Denmark	Denmark	M Topp, P Udall
13	Viterbo province	Italy	MG Torrioli, M Miceli
14	Gelderland	Netherlands	M Wichers