

Data quality Indicators 2004-2008, 29 registries (Created June 2010)

	EUROCAT average	Austria (Styria)	Belgium (Antwerp)	Belgium (Hainaut)	Croatia (Zagreb)	Denmark (Odense)	France (Ile de la Reunion)	France (Paris)	France (Strasbourg)	Germany (Mainz)	Germany (Saxony Anhalt)	Ireland (Cork & Kerry)	Ireland (Dublin)	Ireland (South East)	Italy (Emilia Romagna)	Italy (Tuscany)	Malta	Netherlands (Northern)	Norway	Poland (Wielkopolska)	Portugal (South)	Spain (Barcelona)	Spain (Basque Country)	Switzerland (Vaud)	Ukraine	UK (E Mid & S York)	UK (Northern England)	UK (Thames Valley)	UK (Wales)	UK (Wessex)	
<b>ASCERTAINMENT</b>																															
Total no. of cases		1717	2173	1484	582	759	1860	4154	889	620	2779	478	2255	462	3436	2942	557	2183	6720	3333	1060	1051	1734	1360	2666	7026	3811	2264	5903	2891	
Total congenital anomaly prevalence	<b>239.3</b>	331.5	221.6	236.52	183.6	282.7	251.6	311.0	348.8	488.2	319.9	276.6	183.7	128.8	174.4	195.4	281.5	238.8	383.6	231.3	111.2	177.9	216.0	368.6	233.2	200.3	234.8	183.5	348.3	206.0	
Spina bifida / Anencephaly ratio	<b>1.33</b>	3.10	1.96	2.27	1.25	1.09	1.52	1.12	1.06	2.50	2.57	2.67	1.00	1.56	1.60	1.84	5.00	3.50	3.83	1.83	0.83	0.71	0.94	1.06	1.07	1.27	0.89	1.29	0.80		
Neural Tube Defects prevalence	<b>10.2</b>	9.7	8.9	9.4	4.4	10.1	17.0	13.3	15.3	13.4	9.9	13.9	6.1	6.7	5.4	5.4	11.1	7.3	10.4	9.2	2.0	10.0	10.1	13.0	18.5	11.2	13.6	10.5	13.2	11.3	
Selected cardiac prevalence	<b>13.5</b>	20.5	14.1	12.4	10.4	11.9	11.4	14.1	18.0	18.9	15.2	12.7	16.5	10.0	11.7	10.5	18.7	15.7	12.1	7.6	4.1	17.6	12.8	14.6	13.9	11.7	20.1	12.7	17.2	16.6	
Selected postnatal diagnosis prevalence	<b>18.0</b>	33.2	24.4	14.7	9.5	19.4	19.6	26.8	33.0	28.3	29.0	20.3	18.7	7.8	15.8	15.0	18.7	18.5	11.8	11.0	4.7	21.2	28.0	39.6	16.5	11.8	19.0	15.6	28.0	15.3	
Non-chromosomal syndrome prevalence	<b>7.8</b>	11.2	10.1	7.8	2.8	11.2	15.2	9.1	11.8	15.7	7.0	10.4	9.7	5.9	5.6	3.5	8.1	10.2	6.8	1.7	0.7	7.4	6.0	20.3	9.0	4.2	12.3	7.9	13.1	10.5	
Down syndrome: Observed/Expected ratio by maternal age	<b>0.87</b>	1.01	0.62	-	0.63	1.17	-	1.44	1.53	1.42	0.94	0.96	0.90	0.70	0.66	0.56	1.15	0.72	0.92	0.72	0.33	0.90	1.04	1.42	0.99	0.89	1.14	0.96	1.12	1.11	
Prevalence malformed SB 20-27 weeks	<b>2.06</b>	1.93	1.84	2.39	0.95	1.86	2.03	1.05	3.14	7.09	2.65	2.89	1.79	0.28	0.05	0.93	1.01	1.86	1.26	0.90	0.21	0.34	0.25	1.90	3.24	3.22	3.45	3.00	4.43	3.42	
Prevalence malformed SB >= 28 weeks	<b>3.02</b>	1.54	3.16	1.91	0.63	3.72	3.52	2.99	2.75	6.30	2.53	9.84	11.08	1.67	0.81	0.93	5.56	3.17	2.85	1.25	0.21	1.35	1.12	2.44	6.03	2.82	3.02	4.13	2.89	4.63	
% missing SB gestational age	<b>1</b>	0	6	4	17	0	0	0	0	0	0	0	0	0	11	7	0	0	0	3	0	17	0	0	1	0	0	0	1	0	
<b>ACCURACY OF DIAGNOSIS</b>																															
% MM among non-syndromes/non-chromosomal	<b>12.1</b>	22.5	16.8	14.4	9.8	10.2	12.1	12.5	14.5	5.0	16.9	12.6	11.7	12.8	12.2	8.7	11.0	13.4	6.6	9.6	10.7	29.8	16.0	17.7	13.1	10.4	10.1	12.2	12.7	12.2	
% SB with postmortem carried out	<b>42</b>	50	25	71	33	67	17	-	67	29	84	27	58	29	58	57	77	50	-	25	75	-	73	69	54	5	62	41	58	65	
% SB with postmortem (results known)	<b>35</b>	39	19	71	33	67	15	-	67	29	67	23	58	29	58	47	77	50	-	22	50	-	73	69	51	5	62	40	53	0	
% TOPFA with postmortem carried out	<b>31</b>	57	19	56	52	36	9	-	73	49	76	illegal	illegal	illegal	46	37	illegal	40	-	illegal	49	-	68	52	45	5	54	27	38	35	
% TOPFA with postmortem (results known)	<b>26</b>	55	15	56	34	36	9	-	73	49	67	illegal	illegal	illegal	42	25	illegal	40	-	illegal	31	-	66	51	44	5	54	25	36	0	
% Chromosomals with karyotype carried out	<b>58</b>	97	95	96	83	100	90	-	100	53	95	98	98	83	99	90	86	99	-	80	94	-	98	99	67	35	-	1	96	67	
% Chromosomals with karyotype (results known)	<b>56</b>	95	31	96	67	98	90	-	100	51	95	87	97	98	98	88	86	99	-	76	91	-	98	99	66	34	-	0	93	67	
% Chromosomals with karyotype text #	<b>59</b>	95	33	82	65	98	96	-	99	31	95	90	97	82	0	85	88	99	-	74	88	99	98	100	67	34	97	1	99	66	
% Non-chromosomal MM with known karyotype	<b>23</b>	17	31	58	12	53	48	-	73	8	22	35	38	25	0	33	48	63	-	16	30	69	52	10	4	7	1	30	0		
% Down syndrome with Congenital heart defects or duodenal atresia (Livebirths)	<b>45</b>	71	54	28	44	30	35	43	32	57	54	52	55	53	32	41	58	47	55	44	33	43	51	67	59	28	48	28	59	34	
Prev selected ICD10 Q-chapter/BPA extension codes	<b>12.8</b>	35.5	12.6	NA	12.3	26.8	25.7	NA	21.2	6.3	44.7	17.4	6.1	3.1	11.2	8.8	47.0	11.7	0.6	0.2	2.2	20.0	20.6	48.0	15.3	9.7	15.0	5.6	24.8	15.4	
Prev selected unspecified ICD10 Q-chapter codes	<b>8.9</b>	4.4	15.9	NA	2.5	1.5	2.8	NA	2.4	3.9	7.7	6.9	8.3	5.9	8.6	9.0	3.0	2.3	22.4	9.7	4.3	4.6	1.9	4.3	2.6	19.1	6.1	9.8	12.1	3.9	
<b>COMPLETENESS OF INFORMATION</b>																															
No. core variables 90% complete (total=12)*	<b>10</b>	11	9	9	11	11	11	11	11	8	10	11	10	10	11	11	10	10	7	8	9	9	10	11	11	11	11	9	11	8	
No. non-core variables 80% complete (total=26)*	<b>9</b>	7	4	6	15	18	14	2	18	6	7	16	7	15	10	12	15	9	2	4	6	0	14	17	19	2	5	3	10	8	
% syndrome text complete	<b>67.8</b>	100	100	100	100	100	100	0.1	100	24	100	100	100	100	77	100	25	100	100	82	100	100	100	100	100	100	100	-	100	100	100
% malformation1 text complete	<b>73</b>	100	100	100	100	100	100	0	100	8	100	100	100	100	80	100	100	100	0	0	12	100	100	100	100	100	100	96	99	100	
No other text information available	<b>4</b>							X							X				X		X										
<b>TIMELINESS (Full members)</b>																															
2008 data transmission by February 2010	<b>21</b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
<b>DENOMINATOR INFORMATION</b>																															
80% of Maternal age denoms by 5yr groups 04-08	<b>25</b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Availability monthly denoms 2004-2008	<b>15</b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

# some registries code "not known" for karyotype testing, yet have specified the karyotype text information in the sp\_karyo variable field

"-" indicates no data available

X indicates no text information available for the remaining "specify text" variables

\* years of data 2005-2008 only

Prev = prevalence per 10,000 births

SB= Stillbirths

TOP= Termination of pregnancy for fetal anomaly

MM = Multiple malformations