

## Supplemental Information

**SUPPLEMENTAL TABLE 4** EUROCAT Congenital Anomaly Subgroups in EUROlinkCAT

EUROCAT Subgroups	ICD10-BPA	ICD9-BPA
All anomalies <sup>a</sup>	Q-chapter, D215, D821, D1810, P350, P351, P371	74, 75, 27910, 2281, 76076, 76280, 7710, 7711, 77121
Structural anomalies		
Spina Bifida	Q05	741
Hydrocephalus	Q03	7423
Severe microcephaly	Q02	7421
Congenital cataract	Q120	74332
Congenital Heart Defects (CHD)	Q20-Q26	745, 746, 7470-7474
Severe CHD	Q200, Q201, Q203, Q204, Q212, Q213, Q220, Q224, Q225, Q226, Q230, Q232, Q233, Q234, Q251, Q252, Q262	74500, 74510, 7452, 7453, 7456, 7461, 7462, 74600, 7463, 7465, 7466, 7467, 7471, 74720, 74742
Transposition of great vessels	Q203	74510
Ventricular septal defect	Q210	7454
ASD	Q211	7455
AVSD	Q212	7456
Tetralogy of Fallot	Q213	7452
Pulmonary valve stenosis	Q221	74601
Aortic valve atresia/stenosis	Q230	7463
Mitral valve anomalies	Q232, Q233	7465, 7466
Hypoplastic left heart	Q234	7467
Coarctation of aorta	Q251	7471
Patent ductus arteriosus as only CHD in term infants (GA +37 wk)	Q250	7470
Cystic adenomatous malformation of lung	Q3380	No code
Cleft lip with or without cleft palate	Q36, Q37	7491, 7492
Cleft palate	Q35	7490
Esophageal atresia with/ without trachea-esophageal fistula	Q390-Q391	75030-75031
Duodenal atresia or stenosis	Q410	75110
Atresia or stenosis of other parts of small intestine	Q411-Q418	75111-75112
Anorectal atresia and stenosis	Q420-Q423	75121-75124
Diaphragmatic hernia	Q790	75661
Gastroschisis	Q793	75671
Omphalocele	Q792	75670
Multicystic renal dysplasia	Q6140, Q6141	75316
Congenital hydronephrosis	Q620	75320
Hypospadias	Q54	75260
Limb reduction defects	Q71-Q73	7552-7554
Craniosynostosis	Q750	75600
Chromosomal syndromes		
Down syndrome	Q90	7580
Trisomy 13	Q914-Q917	7581
Trisomy 18	Q910-Q913	7582
Turner syndrome	Q96	75860, 75861, 75862, 75869
Klinefelter syndrome	Q980-Q984	7587

More rare CAs<sup>17</sup> are not included in this table because they are not analyzed in this article, but will be investigated in further EUROlinkCAT papers. ASD, atrial septal defect; AVSD, atrioventricular septal defect; BPA, British Paediatric Association; GA, gestational age; ICD, International Statistical Classification of Diseases and Related Health Problems.

<sup>a</sup> All anomalies = all cases of CA, excluding cases with only minor anomalies as defined in Section 3.2 in Guide 1.4 for cases born post-2005. Cases with >1 anomaly are only counted once in the "All Anomalies" subgroup.<sup>21</sup>

**SUPPLEMENTAL TABLE 5** Results of the Sensitivity Analysis: Survival Estimates for All Registries and After Excluding Each of the Specified Registry in Turn (with Difference in Survival, %) by Specific Congenital Anomaly, 13 EUROCAT Registries in 9 European Countries, 2005 to 2014

Congenital anomaly groups and subgroups	Survival Estimates, % (Difference in Survival Estimates, % After Exclusion of the Named Registries One By One												
	Countries			Italy			Spain			UK			
All registries	Denmark	Finland	France	Emilia Romagna	Tuscany	Malta	Netherlands	Norway	Valencian Region	Midlands	Thames Valley	Wessex	Wales
Any isolated anomaly <sup>a</sup>	96.9	96.7 (0.1)	96.7 (0.2)	96.9 (0.0)	96.8 (0.1)	97.0 (-0.1)	96.8 (0.1)	96.8 (0.1)	96.9 (-0.1)	97.0 (-0.1)	97.0 (-0.1)	97.0 (-0.1)	96.8 (0.1)
Nervous System													
Spina bifida	96.6	96.6 (0.0)	96.2 (0.4)	97.3 (-0.7)	96.6 (0.0)	96.7 (-0.1)	96.9 (-0.3)	96.4 (0.2)	96.3 (0.3)	96.6 (0.0)	96.3 (0.3)	96.3 (0.3)	96.7 (0.0)
Congenital hydrocephalus (excluding spina bifida)	92.9	92.9 (0.0)	92.4 (0.5)	91.7 (1.2)	92.4 (0.6)	93.3 (-0.4)	93.6 (-0.7)	94.0 (-1.0)	93.4 (-0.5)	92.9 (0.0)	92.2 (0.7)	92.8 (0.1)	92.6 (0.3)
Severe microcephaly <sup>b</sup>	95.7	95.7 (0.0)	95.5 (0.2)	95.5 (0.3)	95.7 (0.0)	95.7 (0.0)	96 (-0.3)	95.7 (0.0)	96.7 (-1.0)	95.7 (0.0)	95.8 (-0.1)	96 (-0.2)	90.1 (5.7)
Eye													
Congenital cataract	99.3	99.4 (-0.1)	98.9 (0.4)	99.2 (0.0)	99.6 (-0.3)	99.1 (0.1)	99.2 (0.1)	99.5 (-0.2)	99.1 (0.2)	99.3 (0.0)	99.4 (-0.1)	99.3 (0.0)	99.0 (0.3)
Congenital Heart Defects (CHD)													
All CHD	95.3	95.2 (0.2)	94.9 (0.4)	95.3 (0.0)	95.2 (0.1)	95.4 (-0.1)	95.4 (-0.1)	95.1 (0.2)	95.3 (0.0)	95.7 (-0.4)	95.6 (-0.3)	95.7 (-0.4)	95.2 (0.1)
Severe CHD <sup>c</sup>	86.7	86.6 (0.2)	85.9 (0.8)	87 (-0.3)	86.4 (0.4)	87.0 (-0.3)	87.0 (-0.3)	86.5 (0.2)	86.8 (-0.1)	86.7 (0.0)	87.1 (-0.3)	86.8 (-0.1)	86.5 (0.2)
Transposition of great vessels	91.7	91.5 (0.2)	91.8 (-0.1)	91.6 (0.1)	91.7 (0.1)	91.8 (-0.1)	92.1 (-0.4)	90.8 (0.9)	92.1 (-0.4)	91.2 (0.5)	92.0 (-0.3)	91.4 (0.3)	91.3 (0.5)
Ventricular septal defect	98.1	97.9 (0.2)	98.0 (0.2)	98.0 (0.1)	98.0 (0.1)	98.0 (0.1)	98.2 (-0.1)	98.0 (0.1)	98.2 (-0.1)	98.3 (-0.2)	98.3 (-0.2)	98.2 (-0.1)	98.1 (0.0)
Atrial septal defect	97.7	97.6 (0.1)	97.5 (0.2)	97.6 (0.2)	97.7 (0.0)	97.5 (0.2)	98.0 (-0.2)	97.7 (0.1)	97.8 (-0.1)	98.0 (-0.2)	97.9 (-0.2)	98.0 (-0.2)	97.5 (0.2)
Atroventricular septal defect	87.0	87.6 (-0.6)	86.0 (1.0)	86.3 (0.7)	86.2 (0.8)	87.4 (-0.4)	87.0 (0.0)	86.3 (0.7)	86.3 (0.7)	86.9 (0.1)	87.7 (-0.7)	86.9 (0.1)	87.9 (-0.9)
Tetralogy of Fallot	96.6	96.7 (-0.1)	96.5 (0.1)	96.7 (-0.1)	96.5 (0.1)	96.8 (-0.2)	96.6 (0.1)	96.4 (0.2)	96.5 (0.1)	96.4 (0.2)	97.1 (-0.4)	96.4 (0.2)	96.5 (0.2)
Pulmonary valve stenosis	98.4	98.4 (0.0)	98.2 (0.2)	98.2 (0.2)	98.4 (0.0)	98.2 (0.1)	98.3 (0.1)	98.3 (0.1)	98.6 (-0.2)	98.5 (-0.1)	98.3 (0.1)	98.5 (-0.1)	98.3 (0.1)
Aortic valve atresia/ stenosis	91.2	91.2 (0.0)	89.7 (1.5)	91.1 (0.1)	90.5 (0.7)	91.8 (-0.6)	90.8 (0.4)	92.3 (-1.1)	90.9 (0.3)	90.9 (0.3)	91.4 (-0.2)	90.9 (0.3)	90.3 (0.9)
Mitral valve anomalies	89.5	89.5 (0.0)	89.2 (0.3)	89.5 (0.0)	89.4 (0.1)	89.7 (-0.2)	89.5 (0.0)	91.1 (-1.6)	89.8 (-0.3)	89.5 (0.0)	89.5 (0.1)	89.5 (0.0)	89.2 (0.4)
Hypoplastic left heart	51.6	51.6 (0.0)	48.1 (3.6)	54.2 (-2.6)	51.5 (0.1)	51.7 (0.0)	52.3 (-0.7)	50.6 (1.0)	53.1 (-1.5)	50.4 (1.2)	51 (0.6)	50.4 (1.2)	50.5 (1.1)
Coarctation of aorta	93.3	93.4 (-0.1)	93.1 (0.2)	93 (0.3)	93 (0.3)	93.3 (0.0)	93.7 (-0.4)	92.7 (0.6)	93.8 (-0.5)	93.4 (-0.1)	93.8 (-0.4)	93.5 (-0.2)	93.4 (-0.1)
Patent ductus arteriosus as only CHD in term infants (≥37 wk)	98.9	99 (-0.1)	99 (-0.1)	98.9 (0.0)	99.2 (-0.3)	98.9 (0.0)	98.9 (0.0)	99.0 (-0.1)	98.5 (0.4)	99.3 (-0.4)	98.9 (0.0)	99.3 (-0.4)	98.7 (0.2)
Respiratory system													
Cystic adenomatous malformation of lung	98.7	98.7 (0.0)	98.7 (0.0)	98.7 (0.0)	98.8 (-0.1)	98.7 (0.0)	98.7 (0.0)	98.7 (0.0)	98.7 (0.0)	98.1 (0.6)	98.8 (-0.1)	98.1 (0.6)	99.0 (-0.3)

**SUPPLEMENTAL TABLE 5 Continued**

Congenital anomaly groups and subgroups	Survival Estimates, % (Difference in Survival Estimates, % After Exclusion of the Named Registries One By One																			
	Denmark		Finland		France		Italy			Malta		Netherlands		Norway		Spain		UK		
	registries	Funen	Finland	Finland	Paris	Paris	Emilia Romagna	Tuscany	Malta	Malta	Northern	Norway	Norway	Valencian Region	Midlands	East Midlands	Thames Valley	Wessex	Wales	
<b>Orofacial clefts</b>																				
Cleft lip with or without cleft palate	99.8	99.8 (0.0)	99.7 (0.1)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)
Cleft palate	99.6	99.6 (0.0)	99.4 (0.1)	99.7 (0.1)	99.7 (0.1)	99.7 (0.1)	99.7 (0.1)	99.5 (0.0)	99.6 (0.0)	99.5 (0.0)	99.4 (0.1)	99.4 (0.1)	99.6 (0.1)	99.5 (0.0)	99.5 (0.0)	99.5 (0.0)	99.5 (0.0)	99.5 (0.0)	99.5 (0.1)	99.5 (0.1)
<b>Digestive system</b>																				
Esophageal atresia with or without tracheo-esophageal fistula	96.8	96.8 (0.0)	96.9 (0.1)	96.6 (0.2)	96.5 (0.2)	96.5 (0.2)	97.0 (0.3)	96.8 (0.0)	96.8 (0.0)	96.8 (0.0)	96.4 (0.4)	96.4 (0.4)	96.9 (0.2)	96.8 (0.1)	96.6 (0.1)	96.8 (0.1)	96.6 (0.1)	96.8 (0.1)	96.7 (0.1)	96.7 (0.1)
Duodenal atresia or stenosis	97.7	97.7 (0.0)	97.3 (0.4)	97.8 (0.1)	97.7 (0.1)	97.7 (0.1)	97.9 (0.1)	97.9 (0.1)	97.7 (0.0)	97.7 (0.0)	97.5 (0.3)	97.5 (0.3)	97.9 (0.1)	97.8 (0.0)	97.8 (0.0)	97.8 (0.0)	97.8 (0.0)	97.8 (0.0)	97.7 (0.0)	97.7 (0.0)
Atresia or stenosis of other parts of small intestine	95.6	95.6 (0.0)	95.8 (0.2)	95.8 (0.2)	95.8 (0.2)	95.8 (0.2)	95.7 (0.1)	95.7 (0.1)	95.6 (0.0)	95.6 (0.0)	95.0 (0.7)	95.0 (0.7)	95.5 (0.2)	95.6 (0.0)	95.5 (0.1)	95.5 (0.1)	95.5 (0.1)	95.5 (0.2)	96.1 (0.5)	96.1 (0.5)
Anorectal atresia and stenosis	98.6	98.8 (0.2)	98.2 (0.4)	98.5 (0.0)	98.5 (0.0)	98.5 (0.0)	98.7 (0.1)	98.7 (0.1)	98.6 (0.0)	98.6 (0.0)	98.3 (0.2)	98.3 (0.2)	98.4 (0.2)	98.6 (0.0)	98.6 (0.0)	98.6 (0.0)	98.6 (0.0)	98.5 (0.1)	98.6 (0.0)	98.6 (0.0)
Diaphragmatic hernia	74.2	74.2 (0.0)	73.3 (0.9)	74.5 (0.3)	75.0 (0.8)	75.0 (0.8)	73.2 (1)	74.1 (0.1)	74.1 (0.1)	74.2 (0.0)	73.4 (0.8)	73.4 (0.8)	74.7 (0.5)	74.2 (0.0)	73.5 (0.7)	74.2 (0.0)	74.2 (0.0)	74.2 (0.0)	75.4 (1.2)	75.4 (1.2)
<b>Abdominal wall</b>																				
Gastroschisis	97.2	97.2 (0.0)	97.4 (0.3)	97.2 (0.0)	97.3 (0.1)	97.3 (0.1)	97.1 (0.0)	97.2 (0.0)	97.2 (0.0)	97.2 (0.0)	97.0 (0.2)	97.0 (0.2)	97.4 (0.2)	97.2 (0.0)	97.5 (0.4)	97.2 (0.0)	97.5 (0.4)	96.7 (0.4)	96.6 (0.6)	96.6 (0.6)
Omphalocele	92.7	92.7 (0.0)	91.8 (0.9)	91.9 (0.8)	92.8 (0.1)	92.8 (0.1)	92.6 (0.1)	92.7 (0.0)	92.7 (0.0)	92.5 (0.1)	92.5 (0.2)	92.5 (0.2)	93.5 (0.9)	92.7 (0.0)	93.4 (0.7)	92.4 (0.3)	92.4 (0.3)	92.4 (0.3)	93.1 (0.4)	93.1 (0.4)
<b>Urinary system</b>																				
Multicystic renal dysplasia	97.6	97.5 (0.1)	97.4 (0.3)	97.8 (0.2)	97.6 (0.0)	97.6 (0.0)	97.6 (0.0)	97.6 (0.0)	97.9 (0.3)	97.6 (0.0)	97.6 (0.0)	97.6 (0.0)	97.4 (0.2)	97.6 (0.0)	97.7 (0.1)	97.6 (0.0)	97.7 (0.1)	97.5 (0.1)	97.3 (0.3)	97.3 (0.3)
<b>Congenital hydronephrosis</b>																				
Congenital hydronephrosis	99.7	99.7 (0.0)	99.6 (0.1)	99.7 (0.0)	99.7 (0.0)	99.7 (0.0)	99.7 (0.0)	99.7 (0.0)	99.7 (0.0)	99.7 (0.0)	99.6 (0.1)	99.6 (0.1)	99.7 (0.0)	99.7 (0.0)	99.7 (0.0)	99.7 (0.0)	99.7 (0.0)	99.7 (0.0)	99.7 (0.0)	99.7 (0.0)
<b>Genital</b>																				
Hypospadias	99.8	99.7 (0.0)	99.7 (0.0)	99.8 (0.0)	99.7 (0.0)	99.7 (0.0)	99.7 (0.0)	99.7 (0.0)	99.7 (0.0)	99.7 (0.0)	99.7 (0.0)	99.7 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.8 (0.0)	99.7 (0.0)	99.7 (0.0)
<b>Limb</b>																				
Limb reduction defects	99.2	99.3 (0.0)	99.3 (0.1)	99.2 (0.0)	99.1 (0.1)	99.1 (0.1)	99.2 (0.0)	99.2 (0.0)	99.2 (0.0)	99.2 (0.0)	99.0 (0.2)	99.0 (0.2)	99.2 (0.0)	99.2 (0.0)	99.2 (0.0)	99.2 (0.0)	99.2 (0.0)	99.2 (0.0)	99.3 (0.1)	99.3 (0.1)
<b>Musculoskeletal</b>																				
Craniosynostosis	99.6	99.6 (0.0)	99.4 (0.3)	99.6 (0.0)	99.7 (0.1)	99.7 (0.1)	99.6 (0.0)	99.6 (0.0)	99.6 (0.0)	99.6 (0.0)	99.6 (0.0)	99.6 (0.0)	99.6 (0.1)	99.6 (0.0)	99.6 (0.0)	99.6 (0.0)	99.6 (0.0)	99.6 (0.0)	99.5 (0.1)	99.5 (0.1)
<b>Chromosomal</b>																				
Down syndrome	94.3	94.4 (0.1)	94.2 (0.2)	94.7 (0.4)	94.1 (0.3)	94.0 (0.3)	94.0 (0.3)	94.6 (0.3)	94.6 (0.3)	94.2 (0.1)	94.1 (0.2)	94.1 (0.2)	94.4 (0.1)	94.2 (0.2)	94.1 (0.2)	94.2 (0.2)	94.2 (0.2)	94.2 (0.2)	94.5 (0.2)	94.5 (0.2)
Down syndrome with CHD and digestive system anomaly	88.6	88.6 (0.0)	88.6 (0.0)	88.6 (0.0)	88.6 (0.0)	88.6 (0.0)	88.6 (0.0)	88.6 (0.0)	88.6 (0.0)	88.6 (0.0)	86.9 (1.7)	86.9 (1.7)	89.9 (1.3)	88.2 (0.3)	89.3 (0.7)	88.2 (0.3)	88.2 (0.3)	88.2 (0.3)	89.3 (0.7)	89.3 (0.7)

SUPPLEMENTAL TABLE 5 Continued

Congenital anomaly groups and subgroups	Survival Estimates, % (Difference in Survival Estimates, %) After Exclusion of the Named Registries One By One																			
	All registries	Denmark		Finland		France		Italy			Malta		Netherlands		Norway		Spain		UK	
			Funen	Finland	Finland	Paris	Emilia Romagna	Tuscany	Malta	Northern	Norway	Valencian Region	Midlands	Thames Valley	Wessex	Wales				
Down syndrome with any CHD, but not digestive system anomaly	92.3	92.5 (-0.2)	92.3 (0.0)	92.8 (-0.5)	92.4 (-0.1)	92.2 (0.1)	92.3 (-0.1)	92.3 (0.0)	91.9 (0.4)	92.1 (0.2)	92.2 (0.1)	91.8 (0.5)	92.2 (0.1)	92.2 (0.1)	92.2 (0.1)	92.2 (0.1)	92.2 (0.1)	92.2 (0.1)	92.2 (0.1)	92.4 (-0.1)
Down syndrome with any digestive system anomaly, but not CHD	92.8	92.8 (0.0)	92.8 (0.0)	93.4 (-0.6)	93.1 (-0.3)	93.4 (-0.6)	92.8 (0.0)	92.8 (0.0)	95.1 (-2.3)	93.1 (-0.3)	92.3 (0.5)	92.8 (0.0)	92.3 (0.5)	92.3 (0.5)	92.8 (0.0)	92.3 (0.5)	92.3 (0.5)	92.3 (0.5)	92.3 (0.5)	93.2 (-0.4)
Down syndrome without CHD and digestive system anomaly	97.6	97.7 (-0.1)	97.6 (0.0)	97.7 (-0.1)	97.3 (0.3)	97.4 (0.2)	97.7 (-0.1)	97.5 (0.1)	97.5 (0.1)	97.5 (0.1)	97.6 (0.0)	97.5 (0.1)	97.6 (0.0)	97.5 (0.1)	97.6 (0.0)	97.5 (0.1)	97.6 (0.0)	97.6 (0.0)	97.6 (0.0)	97.7 (0.0)

ASD, atrial septal defect; AVSD, atrioventricular septal defect.

<sup>a</sup> An isolated CA was defined as a structural CA in 1 organ system only or if coexisting anomalies were a consequence of a single primary anomaly.

<sup>b</sup> Reduction in the size of the brain with a head circumference  $>3$  SDs below the mean for sex, gestational age, and ethnic origin (EUROCAT definition<sup>42</sup>).

<sup>c</sup> Severe CHD included the following CHD subgroups: common arterial truncus, double outlet right ventricle, transposition of great vessels, single ventricle, atrioventricular septal defect, tetralogy of Fallot, pulmonary valve atresia, tricuspid atresia and stenosis, Ebstein anomaly, hypoplastic right heart, aortic valve atresia and stenosis, mitral valve anomalies, HLH, coarctation of aorta, aortic atresia and interrupted aortic arch, and total anomalous pulmonary venous return.