

Appendix

Appendix 1: Full list of congenital anomalies by severity

Organ System	Anomaly	Classification
Heart	Atrioventricular septal defect (AVSD)	Severe
Heart	Coarctation of the aorta (CoA)	Severe
Heart	Hypoplastic left heart	Severe
Heart	Pulmonary valve atresia	Severe
Heart	Aortic and mitral valves defects	Severe
Heart	Tetralogy of Fallot (ToF)	Severe
Heart	Transposition of great vessels	Severe
Heart	Tricuspidal valve atresia	Severe
Heart	Ventricular septal defect (VSD)	Moderate
Heart	Atrial septal defect (ASD)	Moderate
Heart	Pulmonary valve stenosis	Moderate
Heart	Persistent foramen ovale	Mild

Lung	Pulmonary hypoplasia	Severe
Lung	Cystic adenomatous malformation of lung	Severe
Lung	Chylotorax	Severe
Lung	Diaphragmatic hernia	Severe
Airways	Choanal atresia	Moderate
Airways	Laryngomalacia/Tracheomalacia	Moderate
Airways	Congenital malformation of larynx	Moderate
Airways	Congenital malformation of trachea and bronchus	Moderate
Mouth / Face	Macroglosia	Moderate
Mouth / Face	Cleft lip	Mild
Mouth / Face	Cleft palate	Mild
Mouth / Face	Cleft palate with cleft lip	Mild
Gastrointestinal tract	Oesophageal atresia	Severe

Gastrointestinal tract	Oesophageal atresia with trachea-oesophageal fistula	Severe
Gastrointestinal tract	Duodenal atresia/ileum atresia	Severe
Gastrointestinal tract	Duodenal stenosis/volvulus	Severe
Gastrointestinal tract	Ano-rectal atresia	Severe
Gastrointestinal tract	Hirschsprung disease	Severe
Gastrointestinal tract	Malformation of gallbladder, bile ductus and liver	Severe
Gastrointestinal tract	Gastroschisis	Severe
Gastrointestinal tract	Omphalocele	Severe
Gastrointestinal tract	Ano-rectal stenosis	Moderate
Gastrointestinal tract	Inguinal or umbilical hernia	Mild
Kidney / urinary tract	Cystic kidney disease	Severe
Kidney / urinary tract	Renal agenesis (includes Potter syndrome/fascies)	Severe
Kidney / urinary tract	Renal dysplasia	Severe
Kidney / urinary tract	Ambiguous genitalia / indeterminate sex	Severe
Kidney / urinary tract	Hydronephrosis	Moderate
Kidney / urinary tract	Hypospadia	Moderate

Brain / nervous system	Anencephaly	Severe
Brain / nervous system	Microcephaly	Severe
Brain / nervous system	Hydrocephalus	Severe
Brain / nervous system	Myelomeningocele	Severe
Brain / nervous system	Spina bifida	Severe
Brain / nervous system	Malformations of corpus callosum	Mild
Brain / nervous system	Cyst (arachnoid, choroid plexus)	Mild
Skull	Craniosynostosis/scaphocephalia	Severe
Limbs	Sirenomelia	Severe
Limbs	Reduction defects of lower limb	Severe
Limbs	Reduction defects of upper limb	Severe
Limbs	Hip dislocation	Severe
Limbs	Club foot / talipes equinovarus	Moderate
Limbs	Polydactyly	Mild
Limbs	Syndactyly	Mild

Skeletal system	Skeletal Dysplasia	Severe
Skeletal system	Vertebral malformation,	Severe
Skeletal system	Congenital absence of rib	Mild
Skin	Collodium Baby	Severe
Skin	Hemangioma	Mild
Skin	Aplasia cutis	Mild
Skin	Auricular, preauricular malformation (includes skin tag)	Mild
Eye	Cataract and othe eye malformations	moderate
Chromosomal anomalies	Down's syndrome (trisomy 21)	Severe
Chromosomal anomalies	Edward's syndrome (trisomy 18)	Severe
Chromosomal anomalies	Patau's syndrome (trisomy 13)	Severe
Chromosomal anomalies	Turner's syndrome	Severe

Chromosomal anomalies	Trypoidy	Severe
Complex malformations / Syndroms	Conjoined twins	Severe
Complex malformations / Syndroms	Fetal alcohol syndrome	Severe
Complex malformations / Syndroms	Warfarin syndrome	Severe
Complex malformations / Syndroms	Branchio-oculo facial syndrome	Severe
Complex malformations / Syndroms	CHARGE syndrome	Severe
Complex malformations / Syndroms	Myotonic dystrophia (Steinert)	Severe
Complex malformations / Syndroms	Ellis-van Creveld syndrome	Severe
Complex malformations / Syndroms	Simpson-Golabi-Behmel syndrome	Severe

Complex malformations / Syndroms	Di George syndrome	Severe
Complex malformations / Syndroms	Marfan syndrome	Severe
Complex malformations / Syndroms	Congenital malformation syndromes predominantly associated with short stature (Cornelia de Lange, Prader-willi, Noonan)	Severe
Complex malformations / Syndroms	Congenital malformation syndromes predominantly affecting facial appearance (Moebius, Schinzel-Giedion)	Severe
Complex malformations / Syndroms	Tuberous sclerosis	Severe
Complex malformations / Syndroms	Sacral teratoma	Severe

#Note:

This list includes those congenital anomalies reported by the treating team in the neonatal period.

Unspecific reported items such as “other anomalies of an organ system” were excluded.

Appendix 2: Descriptive statistics of participant characteristics by country

	Belgium	Denmark	Estonia	France	Germany	Italy	Netherlands	Poland	Portugal	UK	Sweden
Infants (N)	752	351	153	1307	758	1134	393	316	724	1745	267
Gestational age, completed weeks, Mean (SD)	28.6 (2.3)	28.0 (2.4)	28.7 (2.2)	28.4 (2.3)	28.2 (2.6)	28.5 (2.4)	28.4 (2.5)	28.1 (2.8)	28.5 (2.2)	28.5 (2.4)	28.2 (2.5)
Male, N (%)	426 (56.6)	185 (52.7)	80 (52.3)	701 (53.6)	407 (53.7)	563 (49.6)	195 (49.6)	176 (55.7)	423 (58.4)	965 (55.3)	145 (54.3)
Singleton, N (%)	464 (61.7)	208 (59.3)	119 (77.8)	881 (67.4)	487 (64.2)	768 (67.7)	274 (69.7)	251 (79.4)	500 (69.1)	1300 (74.6)	185 (69.3)
Twins or more, N (%)	288 (38.3)	143 (40.7)	34 (22.2)	426 (32.6)	271 (35.8)	366 (32.3)	119 (30.3)	65 (20.6)	224 (30.9)	443 (25.4)	82 (30.7)
Birth weight (grams), Mean (SD)	1260.0 (420.8)	1141.6 (415.4)	1287.0 (390.1)	1162.3 (372.1)	1165.1 (418.0)	1195.4 (420.3)	1198.2 (412.1)	1224.7 (474.2)	1149.4 (363.5)	1210.4 (383.9)	1216.7 (436.4)
Congenital anomaly, N (%)	11 (1.5)	23 (6.6)	9 (5.9)	117 (9.0)	99 (13.1)	115 (10.1)	42 (10.7)	90 (28.5)	34 (4.7)	118 (6.8)	22 (8.2)

UK denotes United Kingdom; SD denotes standard deviation.

Appendix 3: PedsQL™ GCS scores by congenital anomaly status and study independent variables

	PedsQL GCS scale	No congenital anomaly, mean (SD)	Congenital anomaly, mean(SD)	Mean difference	95% Confidence interval	P value
Employment status	Employed or other situation	N=2839	N=254			
	Physical functioning	81.8 (20.2)	74.2 (23.1)	7.6	(5.0, 10.2)	<0.001
	Emotional functioning	76.3 (16.7)	74.7 (17.4)	1.6	(-0.5, 3.8)	0.138
	Social functioning	82.9 (18.6)	76.4 (21.9)	6.5	(4.1, 8.9)	<0.001
	School functioning	77.2 (18.9)	68.9 (21.1)	8.3	(5.7, 11.0)	<0.001
	Psychosocial functioning	78.9 (14.9)	73.5 (16.1)	5.4	(3.5, 7.3)	<0.001
	Total score	79.7 (14.8)	73.7 (16.5)	6	(4.1, 7.9)	<0.001
Employment status	At least one parent unemployed	N=326	N=39			
	Physical functioning	74.6 (22.9)	74.8 (25.9)	-0.2	(-8.0, 7.6)	0.959
	Emotional functioning	74.2 (18.7)	69.2 (17.6)	5	(-1.2, 11.2)	0.113
	Social functioning	77.6 (20.1)	76.6 (23.4)	1.1	(-5.8, 8.0)	0.761
	School functioning	69.8 (19.3)	65.4 (23.3)	4.4	(-2.9, 11.7)	0.236
	Psychosocial functioning	73.8 (16.1)	69.9 (18.0)	3.9	(-1.5, 9.3)	0.158
	Total score	74.1 (16.1)	71.3 (18.4)	2.7	(-2.7, 8.2)	0.325
Mother's education	High education ISCED 6-8	N=1326	N=104			
	Physical functioning	83.8(19.2)	74.6(22.3)	9.2	(5.3,13.0)	<0.001
	Emotional functioning	75.6(16.3)	73.4(16.1)	2.2	(-1.0,5.5)	0.183
	Social functioning	83.9(17.6)	73.6(22.4)	10.3	(6.7,13.9)	<0.001
	School functioning	79.4(18.1)	69.8(19.5)	9.6	(5.6,13.6)	<0.001

Mother's education	Intermediate education ISCED 3-5	Psychosocial functioning	79.7(14.2)	72.2(15.5)	7.4	(4.6,10.3)	<0.001
		Total score	80.8(14.1)	72.9(16.1)	7.9	(5.0,10.7)	<0.001
			N=1294	N=131			
		Physical functioning	80.4(21.4)	74.1(24.2)	6.3	(2.4,10.2)	0.001
		Emotional functioning	76.1(17.4)	74.9(17.6)	1.2	(-1.9,4.3)	0.453
		Social functioning	82.2(19.0)	78.0(21.4)	4.2	(0.7,7.7)	0.019
		School functioning	74.9(19.9)	67.2(22.3)	7.8	(3.9,11.6)	<0.001
		Psychosocial functioning	77.8(15.6)	73.5(16.6)	4.3	(1.5,7.1)	0.003
		Total score	78.5(15.7)	73.7(17.1)	4.8	(2.0,7.7)	0.001
			N=495	N=57			
Mother's education	Low education ISCED 0-2	Physical functioning	76.3(20.6)	73.8(24.9)	2.6	(-3.2,8.3)	0.385
		Emotional functioning	77.3(17.4)	74.5(17.4)	2.8	(-2.0,7.6)	0.254
		Social functioning	79.3(20.7)	78.9(21.9)	0.4	(-5.3,6.1)	0.894
		School functioning	71.9(18.3)	68.4(22.5)	3.5	(-2.3,9.4)	0.231
		Psychosocial functioning	76.6(15.5)	74.5(15.8)	2.1	(-2.2,6.4)	0.331
		Total score	76.6(15.3)	74.2(16.7)	2.3	(-1.9,6.6)	0.278
			N=2516	N=230			
Country of birth for mothers	Native	Physical functioning	81.8 (20.0)	76.1 (21.9)	5.7	(3.0, 8.5)	<0.001
		Emotional functioning	76.0 (16.8)	74.2 (17.2)	1.8	(-0.4, 4.1)	0.112
		Social functioning	83.2 (18.2)	77.7 (21.5)	5.5	(3.0, 8.0)	<0.001
		School functioning	77.2 (18.7)	70.4 (20.2)	6.8	(4.0, 9.5)	<0.001
		Psychosocial functioning	78.9 (14.7)	74.2 (15.9)	4.7	(2.7, 6.7)	<0.001
		Total score	79.6 (14.7)	74.7 (16.0)	5	(3.0, 6.9)	<0.001

Non native		N=502	N=46			
	Physical functioning	80.2 (20.6)	75.1 (23.0)	5.1	(1.8, 8.3)	0.002
	Emotional functioning	76.4 (17.3)	74.5 (17.0)	1.9	(-0.8, 4.6)	0.164
	Social functioning	81.7 (19.2)	78.9 (21.3)	2.8	(-0.2, 5.9)	0.067
	School functioning	74.9 (19.2)	68.0 (21.8)	6.9	(3.5, 10.2)	0
	Psychosocial functioning	77.9 (15.3)	74.2 (15.8)	3.7	(1.3, 6.1)	0.002
	Total score	78.5 (15.1)	74.5 (16.3)	4	(1.7, 6.4)	0.001
Mother's age at childbirth						
	25-34	N=1840	N=160			
	Physical functioning	81.1 (20.5)	75.0 (22.6)	6.1	(2.7, 9.4)	<0.001
	Emotional functioning	75.5 (16.7)	74.2 (18.2)	1.4	(-1.4, 4.1)	0.325
	Social functioning	82.0 (18.7)	75.9 (21.9)	6	(3.0, 9.1)	<0.001
	School functioning	76.0 (19.1)	67.9 (20.2)	8.1	(4.7, 11.4)	<0.001
	Psychosocial functioning	78.0 (14.9)	72.7 (16.4)	5.3	(2.9, 7.7)	<0.001
	Total score	78.8 (14.9)	73.4 (16.5)	5.4	(3.0, 7.9)	<0.001
	<25	N=370	N=34			
	Physical functioning	78.5 (23.6)	74.1 (24.2)	4.4	(-3.9, 12.7)	0.299
	Emotional functioning	75.9 (17.5)	69.6 (17.8)	6.3	(0.2, 12.5)	0.044
	Social functioning	81.2 (19.9)	77.3 (24.0)	3.9	(-3.2, 11.0)	0.284
	School functioning	71.6 (19.8)	59.8 (21.6)	11.8	(4.1, 19.6)	0.003
	Psychosocial functioning	76.5 (15.7)	69.5 (17.8)	6.9	(1.3, 12.5)	0.016
	Total score	77.0 (16.1)	70.5 (17.2)	6.5	(0.8, 12.2)	0.026
	>34	N=986	N=103			
	Physical functioning	81.8 (19.8)	72.6 (24.7)	9.1	(5.0, 13.3)	<0.001
	Emotional functioning	76.9 (17.2)	75.0 (16.1)	1.8	(-1.6, 5.3)	0.3

		Social functioning	83.1 (18.7)	76.9 (21.7)	6.3	(2.4, 10.1)	0.001
		School functioning	78.4 (18.5)	71.7 (22.2)	6.7	(2.4, 10.9)	0.002
		Psychosocial functioning	79.5 (15.2)	74.6 (15.7)	4.8	(1.7, 7.9)	0.002
		Total score	80.1 (15.0)	74.1 (17.0)	6	(2.9, 9.0)	<0.001
Parity	Nulliparous		N=1235	N=119			
		Physical functioning	79.9 (21.0)	70.8 (25.1)	9.2	(5.1, 13.2)	
		Emotional functioning	76.5 (16.9)	74.5 (18.0)	2	(-1.2, 5.2)	
		Social functioning	82.4 (19.2)	75.6 (22.8)	6.8	(3.1, 10.5)	
		School functioning	75.3 (19.2)	67.5 (21.9)	7.7	(3.8, 11.7)	
		Psychosocial functioning	78.2 (15.2)	72.7 (17.0)	5.6	(2.7, 8.5)	
		Total score	78.7 (15.2)	72.2 (17.4)	6.5	(3.6, 9.4)	
	Multiparous		N=1931	N=169			
		Physical functioning	81.7 (20.4)	76.8 (21.5)	4.9	(1.6, 8.1)	<0.001
		Emotional functioning	75.7 (17.0)	73.6 (17.1)	2	(-0.6, 4.7)	0.225
		Social functioning	82.2 (18.6)	77.1 (21.5)	5.1	(2.1, 8.1)	<0.001
		School functioning	76.9 (19.0)	69.2 (20.7)	7.7	(4.4, 11.1)	<0.001
		Psychosocial functioning	78.3 (15.0)	73.4 (15.8)	4.9	(2.5, 7.3)	<0.001
		Total score	79.2 (15.0)	74.3 (16.0)	4.9	(2.5, 7.3)	<0.001
Multiples	Singleton		N=2174	N=205			
		Physical functioning	80.3 (20.8)	73.1 (24.1)	7.2	(4.2, 10.2)	<0.001
		Emotional functioning	75.2 (17.1)	73.7 (17.3)	1.5	(-1.0, 3.9)	0.236
		Social functioning	81.5 (18.9)	75.3 (21.8)	6.2	(3.5, 9.0)	<0.001
		School functioning	75.6 (19.1)	66.7 (21.7)	8.8	(5.8, 11.8)	<0.001
		Psychosocial functioning	77.5 (15.2)	72.1 (16.0)	5.4	(3.2, 7.6)	<0.001
		Total score	78.3 (15.2)	72.4 (16.7)	5.9	(3.7, 8.1)	<0.001

Multiples		N=1022	N=92			
	Physical functioning	82.4 (20.2)	76.3 (22.1)	6.2	(1.8, 10.5)	0.005
	Emotional functioning	77.6 (16.4)	74.4 (17.9)	3.2	(-0.3, 6.7)	0.074
	Social functioning	83.9 (18.6)	79.0 (22.3)	4.8	(0.8, 8.9)	0.02
	School functioning	77.7 (19.1)	71.8 (19.9)	5.9	(1.3, 10.4)	0.011
	Psychosocial functioning	79.9 (14.9)	75.0 (17.0)	4.8	(1.6, 8.0)	0.003
	Total score	80.6 (14.8)	75.4 (16.7)	5.2	(2.0, 8.3)	0.002
Gender	Female	N=1488	N=138			
	Physical functioning	81.5 (20.0)	73.2 (24.4)	8.3	(4.7, 11.8)	<0.001
	Emotional functioning	76.6 (16.8)	72.4 (18.7)	4.2	(1.2, 7.2)	0.006
	Social functioning	83.7 (17.9)	78.3 (21.1)	5.4	(2.2, 8.5)	0.001
	School functioning	79.1 (18.5)	70.6 (21.8)	8.5	(4.9, 12.1)	<0.001
	Psychosocial functioning	79.8 (14.7)	73.9 (16.8)	5.9	(3.3, 8.5)	<0.001
	Total score	80.3 (14.7)	73.8 (17.1)	6.5	(3.9, 9.1)	<0.001
	Male	N=1708	N=159			
	Physical functioning	80.5 (21.2)	74.8 (22.7)	5.7	(2.2, 9.2)	0.001
	Emotional functioning	75.4 (17.0)	75.3 (16.2)	0.2	(-2.6, 2.9)	0.899
	Social functioning	81.0 (19.5)	74.8 (22.7)	6.2	(3.0, 9.5)	<0.001
	School functioning	73.7 (19.3)	66.4 (20.7)	7.3	(3.9, 10.7)	<0.001
	Psychosocial functioning	76.9 (15.3)	72.3 (15.9)	4.7	(2.2, 7.2)	<0.001
	Total score	77.9 (15.3)	72.9 (16.4)	5	(2.5, 7.5)	<0.001
SGA	<3rd centile	N=668	N=84			
	Physical functioning	81.3 (19.8)	73.7 (21.6)	7.6	(3.0, 12.1)	0.001
	Emotional functioning	75.8 (17.7)	69.3 (18.4)	6.5	(2.5, 10.5)	0.002

	3 rd to 9 th	Social functioning	81.5 (19.4)	74.1 (21.5)	7.4	(2.9, 11.9)	0.001
		School functioning	74.8 (19.4)	64.8 (18.1)	10	(5.3, 14.7)	<0.001
		Psychosocial functioning	77.6 (15.5)	69.5 (15.7)	8.1	(4.6, 11.7)	<0.001
		Total score	78.6 (15.2)	70.6 (15.8)	8	(4.5, 11.5)	<0.001
			N=370	N=35			
		Physical functioning	83.1 (18.8)	74.5 (22.7)	8.6	(2.0, 15.3)	0.011
		Emotional functioning	75.4 (16.8)	72.4 (16.2)	3	(-2.8, 8.8)	0.31
		Social functioning	82.2 (18.3)	78.9 (24.4)	3.3	(-3.3, 9.8)	0.326
		School functioning	76.7 (19.0)	70.8 (23.3)	5.8	(-1.4, 13.1)	0.115
		Psychosocial functioning	78.1 (14.7)	73.7 (17.6)	4.4	(-0.8, 9.6)	0.098
		Total score	79.4 (14.3)	73.9 (18.1)	5.5	(0.4, 10.6)	0.035
			N=2158	N=178			
		Physical functioning	80.5 (21.2)	74.2 (24.6)	6.4	(3.1, 9.6)	<0.001
		Emotional functioning	76.2 (16.7)	76.5 (16.8)	-0.3	(-2.9, 2.3)	0.822
	≥10 th centile	Social functioning	82.5 (18.8)	77.0 (21.7)	5.5	(2.5, 8.4)	<0.001
		School functioning	76.6 (19.0)	69.6 (22.2)	7	(3.7, 10.3)	<0.001
		Psychosocial functioning	78.5 (15.1)	74.6 (16.1)	4	(1.6, 6.3)	0.001
		Total score	79.0 (15.2)	74.5 (16.8)	4.6	(2.2, 6.9)	<0.001
			N=264	N=29			
		Physical functioning	76.1 (22.1)	72.3 (21.6)	3.9	(-4.6, 12.3)	0.372
		Emotional functioning	73.4 (17.9)	70.3 (20.4)	3	(-4.0, 10.0)	0.394
		Social functioning	76.3 (21.1)	73.7 (21.4)	2.6	(-5.5, 10.8)	0.523
		School functioning	70.0 (19.1)	64.5 (24.7)	5.5	(-2.6, 13.6)	0.182
		Psychosocial functioning	73.5 (16.4)	69.3 (18.5)	4.2	(-2.2, 10.6)	0.196
		Total score	74.1 (16.2)	70.0 (18.6)	4.1	(-2.2, 10.5)	0.198
Gestational age	<26						

BPD	26-27		N=581	N=63			
		Physical functioning	79.9 (22.0)	68.0 (24.3)	12	(6.2, 17.7)	<0.001
		Emotional functioning	76.0 (17.3)	72.3 (19.2)	3.7	(-0.9, 8.2)	0.115
		Social functioning	81.5 (19.3)	69.6 (20.0)	11.9	(6.8, 17.0)	<0.001
		School functioning	75.9 (18.8)	60.9 (20.5)	14.9	(9.5, 20.4)	<0.001
		Psychosocial functioning	77.9 (15.4)	67.9 (15.0)	10	(6.0, 14.0)	<0.001
		Total score	78.5 (15.7)	68.0 (15.5)	10.5	(6.4, 14.6)	<0.001
	28-29		N=835	N=75			
		Physical functioning	80.3 (21.2)	76.1 (22.4)	4.2	(-0.8, 9.3)	0.101
		Emotional functioning	76.7 (16.5)	74.7 (18.6)	2	(-1.9, 5.9)	0.321
		Social functioning	82.3 (19.2)	79.0 (22.4)	3.4	(-1.2, 8.0)	0.15
		School functioning	75.3 (20.5)	71.8 (20.6)	3.5	(-2.0, 8.9)	0.208
		Psychosocial functioning	78.3 (15.3)	74.7 (16.8)	3.6	(0.0, 7.3)	0.05
		Total score	78.8 (15.3)	75.1 (16.8)	3.8	(0.1, 7.4)	0.043
	30-31		N=1516	N=130			
		Physical functioning	82.6 (19.4)	76.3 (23.8)	6.3	(2.8, 9.9)	<0.001
		Emotional functioning	76.1 (16.9)	75.1 (15.0)	1	(-2.0, 4.0)	0.53
		Social functioning	83.5 (17.9)	78.8 (22.2)	4.7	(1.4, 8.0)	0.005
		School functioning	77.9 (18.2)	70.8 (20.4)	7.1	(3.5, 10.7)	<0.001
		Psychosocial functioning	79.2 (14.5)	75.4 (15.6)	3.8	(1.2, 6.5)	0.004
		Total score	80.1 (14.4)	75.6 (16.3)	4.5	(1.9, 7.1)	0.001
	No		N=2726	N=234			
		Physical functioning	81.8 (20.1)	76.0 (22.6)	5.8	(3.1, 8.5)	<0.001
		Emotional functioning	76.4 (16.6)	74.2 (17.5)	2.2	(-0.1, 4.4)	0.055

BPD	Yes	Social functioning	83.1 (18.2)	78.5 (22.1)	4.6	(2.1, 7.1)	<0.001
		School functioning	77.2 (18.6)	70.1 (20.6)	7	(4.3, 9.8)	<0.001
		Psychosocial functioning	79.0 (14.6)	74.3 (16.2)	4.7	(2.7, 6.6)	<0.001
		Total score	79.7 (14.6)	74.8 (16.4)	4.9	(3.0, 6.9)	<0.001
		N=394	N=55				
		Physical functioning	75.1 (23.8)	66.4 (24.2)	8.7	(2.0, 15.5)	0.011
		Emotional functioning	73.4 (19.3)	71.7 (17.4)	1.7	(-3.7, 7.1)	0.534
		Social functioning	76.0 (22.3)	67.0 (19.5)	9	(2.8, 15.2)	0.005
		School functioning	69.9 (21.2)	61.4 (20.7)	8.6	(2.1, 15.0)	0.01
		Psychosocial functioning	73.3 (17.5)	66.8 (14.9)	6.5	(1.6, 11.3)	0.009
	Total score	73.7 (17.5)	66.6 (15.7)	7.1	(2.2, 12.0)	0.005	
Severe non-respiratory morbidity	No		N=2813	N=246			
		Physical functioning	82.0 (19.6)	76.4 (21.6)	5.6	(3.0, 8.2)	<0.001
		Emotional functioning	76.4 (16.8)	74.7 (17.2)	1.6	(-0.6, 3.8)	0.143
		Social functioning	83.1 (18.3)	78.7 (21.9)	4.4	(1.9, 6.8)	<0.001
		School functioning	76.9 (18.8)	71.1 (19.4)	5.8	(3.1, 8.5)	<0.001
		Psychosocial functioning	78.9 (14.7)	74.8 (15.7)	4.1	(2.1, 6.0)	<0.001
		Total score	79.7 (14.6)	75.3 (15.8)	4.5	(2.6, 6.4)	<0.001
Severe non-respiratory morbidity	Yes		N=311	N=45			
		Physical functioning	72.6 (26.5)	63.4 (28.4)	9.2	(0.8, 17.6)	0.031
		Emotional functioning	73.8 (17.4)	69.8 (18.8)	4.1	(-1.5, 9.6)	0.149
		Social functioning	75.5 (21.7)	65.6 (19.9)	9.9	(3.1, 16.6)	0.004
		School functioning	69.9 (21.1)	56.3 (23.4)	13.7	(6.7, 20.6)	<0.001

Psychosocial functioning	73.1 (17.2)	64.0 (16.7)	9.2	(3.8, 14.5)	0.001
Total score	73.0 (17.7)	63.9 (18.0)	9.1	(3.5, 14.7)	0.001

SGA: small for gestational age

BPD: bronchopulmonary dysplasia. This is defined as receipt of supplemental oxygen and/or ventilatory support (CPAP or mechanical ventilation) at 36 weeks of postmenstrual age.

Severe non-respiratory morbidity: IntraVentricular Haemorrhage (IVH) grades III-IV, cystic PeriVentricular Leukomalacia (cPVL), Retinopathy Of Prematurity (ROP) stages III-V or Necrotising EnteroColitis (NEC) needing surgery.

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Employed or other situation: Other situation included student, parental leave, home parent and other.

Appendix 4: Sensitivity analysis that excludes Denmark and Germany from the multilevel analysis on the total PedsQL GCS score

		(1)	(2)	(3)		(4)	(5)	(6)
Congenital anomaly (reference: no congenital anomaly)	Yes							
					Mild	-3.5*	-2.8	-2.6
		-4.1***	-3.5***	-2.9**		(1.6)	(1.6)	(1.6)
		(0.9)	(0.9)	(0.9)	Moderate	-2.8*	-2.2	-1.6
						(1.4)	(1.4)	(1.4)
					Severe	-6.7***	-6.1***	-5.2**
						(1.6)	(1.6)	(1.7)
Employment status (reference: Employed or other situation)	At least one parent unemployed	-3.9***	-3.6***	-3.9***	At least one parent unemployed	-3.9***	-3.7***	-3.9***
		(1.0)	(1.0)	(1.0)		(1.0)	(1.0)	(1.0)
Mother's education (reference: High education ISCED 6-8)	Intermediate education ISCED 3-5	-2.0**	-1.9**	-1.9**	Intermediate education ISCED 3-5	-1.9**	-1.9**	-1.8**
		(0.7)	(0.7)	(0.7)		(0.7)	(0.7)	(0.7)
	Low education ISCED 0-2	-2.4**	-2.4*	-2.4*	Low education ISCED 0-2	-2.4*	-2.3*	-2.4*
		(0.9)	(1.0)	(1.0)		(0.9)	(1.0)	(1.0)
Country of birth for mothers (reference: native)	Non-native, European born	1.1	1.1	2.2	Non-native, European born	1.1	1.1	2.2
		(1.4)	(1.4)	(1.5)		(1.4)	(1.4)	(1.5)
	Non-native, non-European born	-5.4***	-5.2***	-5.7***	Non-native, non-European born	-5.4***	-5.2***	-5.8***
		(0.9)	(0.9)	(0.9)		(0.9)	(0.9)	(0.9)
Mother's age at childbirth (years) (reference: 25-34)	<25	-0.9	-0.7	-0.5	<25	-0.9	-0.7	-0.5
		(1.0)	(1.0)	(1.0)		(1.0)	(1.0)	(1.0)

	>34	1.8** (0.7)	1.9** (0.7)	1.8** (0.7)	>34	1.8** (0.7)	1.8** (0.7)	1.7** (0.7)
Parity (reference: multiparous)	Nulliparous		0.3 (0.6)	0.3 (0.6)	Nulliparous		0.3 (0.6)	0.3 (0.6)
Multiples (reference: singleton)	Twins		2.0** (0.8)	1.6* (0.8)	Twins		1.9** (0.8)	1.6* (0.8)
	Triplets		1.2 (2.5)	2.2 (2.5)	Triplets		1.2 (2.5)	2.2 (2.5)
Gender (reference: Female)	Male		-3.0*** (0.5)	-2.8*** (0.5)	Male		-3.0*** (0.5)	-2.8*** (0.5)
SGA (reference: <3rd centile)	3rd to 9th		0.7 (0.9)	0.3 (0.9)	3 to 10		0.8 (0.9)	0.4 (0.9)
	≥10th		1.0 (0.7)	0.5 (0.7)	>10th		1.0 (0.7)	0.5 (0.7)
Gestational age (weeks) (reference: 30-31)	<26		-4.8*** (1.1)	-0.7 (1.2)	<26		-4.8*** (1.1)	-0.7 (1.2)
	26-27		-1.7* (0.8)	0.1 (0.9)	26-27		-1.7* (0.8)	0.1 (0.9)
	28-29		-0.8 (0.7)	-0.4 (0.7)	28-29		-0.8 (0.7)	-0.4 (0.7)
BPD (reference: no BPD)	Yes			-3.7*** (0.9)	Yes			-3.8*** (0.9)
Severe non-respiratory morbidity (reference: no severe non-respiratory morbidity)	Yes			-5.9*** (0.9)	Yes			-5.9*** (0.9)

Model 1 and 4 included (i) SES variables alone; model 2 and 5 included (i) SES variables plus (ii) perinatal variables; and model 3 and 6 included (i) SES variables, (ii) perinatal variables, and (iii) neonatal morbidities.

SGA: small for gestational age

BPD: bronchopulmonary dysplasia. This is defined as receipt of supplemental oxygen and/or ventilatory support (CPAP or mechanical ventilation) at 36 weeks of postmenstrual age.

Severe non-respiratory morbidity: IntraVentricular Haemorrhage (IVH) grades III-IV , cystic PeriVentricular Leukomalacia (cPVL), Retinopathy Of Prematurity (ROP) stages III-V or Necrotising Enterocolitis (NEC) needing surgery.

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Employed or other situation: Other situation included student, parental leave, home parent and other.

Standard errors in parentheses

*** $p < 0.001$, ** $p < 0.01$, * $p < 0.05$

Appendix 5: OLS regression of factors predicting health-related quality of life in very preterm children by country

		Belgium	Denmark	Estonia	France	Germany	Italy	Netherlands	Poland	Portugal	UK	Sweden
Congenital anomaly (reference: no congenital anomaly)	Mild	5.53	-22.18**		2.05	9.27	-6.32*		-5.77		-	-4.50
		(10.45)	(7.81)		(3.53)	(7.23)	(2.97)		(3.30)		(8.63)	(14.52)
	Moderate		3.89	-10.42	-12.79**	-0.59	-2.15	-8.51*	-1.80	4.56	-3.22	-3.34
			(5.67)	(8.53)	(4.45)	(7.30)	(2.73)	(3.46)	(3.91)	(3.98)	(5.15)	(4.46)
	Severe		-0.37	-25.84***	-9.30*	-12.49**	-5.23	-5.16	-7.62*	8.03	1.79	-11.62
			(11.10)	(7.39)	(3.79)	(4.61)	(3.70)	(11.90)	(3.75)	(5.54)	(7.57)	(6.14)
Employment status (reference: Employed or other situation)	At least one parent unemployed	-1.14	-8.94	-16.97***	-3.99*	-13.43*	-0.33	-1.00	-1.86	-0.88	-	4.00
		(4.74)	(4.79)	(3.92)	(1.81)	(6.54)	(1.65)	(4.82)	(3.31)	(1.79)	(3.78)	(6.54)
Mother's education (reference: High education ISCED 6- 8)	Intermediate education ISCED 3-5	-1.82	0.30	-0.48	-2.71	1.04	-1.45	2.17	2.91	-2.29	-2.52	-5.20*
		(2.27)	(2.24)	(2.31)	(1.46)	(2.71)	(1.17)	(2.24)	(2.38)	(1.52)	(1.93)	(2.43)
	Low education ISCED 0-2	-8.30	-4.93	10.48*	-3.90*	-4.80*	-0.61	1.69	-0.60	-4.96**	-2.59	-
		(5.63)	(4.07)	(4.75)	(1.85)	(2.19)	(1.57)	(4.24)	(4.57)	(1.65)	(5.33)	26.26***
Country of birth for mothers (reference: native)	Non-native, European born		-0.78	-47.68***	4.07	9.02*	-0.33	11.55		-7.78*		-14.00**
			(5.17)	(12.50)	(5.35)	(3.92)	(1.51)	(9.63)		(3.64)		(4.83)
	Non-native, non- European born	-1.06	4.13		-5.35***	1.44	-5.73**	5.41		-1.21	-5.54	-5.71
		(4.48)	(3.83)		(1.42)	(3.98)	(1.86)	(3.94)		(2.30)	(3.19)	(3.54)

Mother's age at childbirth (years) (reference: 25-34)	<25	-4.27	0.27	0.66	1.09	4.44	3.63	-8.73*	-0.30	-1.91	2.04	4.69
		(3.44)	(3.70)	(3.33)	(1.92)	(3.69)	(2.31)	(4.21)	(2.87)	(2.12)	(2.78)	(5.13)
	>34	-0.14	-2.09	5.56*	0.20	-2.61	2.99**	2.62	-4.75	-1.44	-2.72	0.46
		(2.73)	(2.35)	(2.38)	(1.53)	(2.20)	(1.10)	(2.73)	(2.88)	(1.44)	(2.13)	(2.66)
Parity (reference: multiparous)	Nulliparous	1.89	1.62	-3.26	-1.85	-4.06	-1.08	5.59*	-0.53	-2.27	1.46	-1.02
		(2.16)	(2.13)	(2.21)	(1.33)	(2.26)	(1.14)	(2.47)	(2.33)	(1.43)	(1.89)	(2.61)
Multiples (reference: singleton)	Twins	-1.26	6.61**	7.67**	1.22	-2.94	0.65	6.88**	0.04	3.17*	5.95**	-1.72
		(2.13)	(2.22)	(2.97)	(1.36)	(2.19)	(1.18)	(2.43)	(2.70)	(1.40)	(2.12)	(2.51)
	Triplets		1.88	9.66*	13.57*	-8.34*	-3.38	6.49	2.82	-0.44	5.93	2.46
			(4.09)	(4.16)	(6.23)	(4.02)	(2.48)	(6.72)	(8.34)	(5.18)	(4.86)	(7.38)
Gender (reference: Female)	Male	-3.42	-4.12*	-1.94	0.39	-0.08	-1.47	-3.53	-3.00	-3.40**	-4.86**	-1.12
		(2.00)	(2.01)	(2.16)	(1.25)	(1.95)	(1.03)	(2.09)	(2.10)	(1.28)	(1.84)	(2.18)
SGA (reference: <3rd centile)	3 rd to 9 th	-0.35	-0.36	-10.74**	0.87	-6.07*	1.50	6.49	-1.16	0.47	1.85	-1.56
		(3.95)	(3.73)	(3.62)	(2.39)	(3.07)	(1.87)	(4.70)	(4.34)	(2.07)	(3.31)	(4.10)
	≥10 th	-0.60	3.52	-8.00**	0.76	-5.01*	-0.79	2.75	-2.31	0.80	5.15*	2.61
		(2.94)	(2.31)	(2.95)	(1.52)	(2.29)	(1.36)	(2.71)	(3.42)	(1.57)	(2.49)	(3.06)
Gestational age (weeks) (reference: 30-31)	<26	-2.98	-5.02	12.24*	-0.46	-2.67	2.20	-8.96*	2.27	0.82	-3.20	-10.88**
		(4.12)	(4.08)	(4.84)	(2.96)	(3.40)	(2.40)	(3.75)	(4.00)	(3.42)	(4.05)	(3.64)
	26-27	-1.90	-0.72	10.32***	-1.08	-4.89	0.69	-0.54	-5.58	0.74	-1.00	-8.13
		(3.10)	(2.44)	(3.03)	(1.81)	(3.08)	(1.51)	(2.80)	(3.13)	(1.74)	(3.08)	(4.26)
	28-29	-2.17	1.77	4.94	0.33	-1.49	1.84	-3.46	-4.11	-0.07	-5.41*	-3.29
		(2.54)	(2.57)	(2.79)	(1.46)	(2.43)	(1.24)	(3.02)	(2.73)	(1.49)	(2.27)	(2.65)
BPD (reference: no BPD)	Yes	-7.14*	1.93	-10.82**	-1.38	-7.91*	-5.21**	1.04	-1.17	-3.41	-5.10*	4.13
		(3.16)	(3.50)	(3.80)	(2.18)	(3.79)	(2.01)	(2.92)	(4.09)	(2.18)	(2.53)	(3.57)

Severe non-respiratory morbidity (reference: no severe non-respiratory morbidity)	Yes										
	-11.67**	1.61	-5.28	-3.28	-2.84	-	6.95***	-3.55	-	12.18**	-
	(3.68)	(3.76)	(3.74)	(2.71)	(3.48)	(1.81)	(3.44)	(2.89)	(2.26)	(3.19)	(4.07)

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BPD: bronchopulmonary dysplasia. This is defined as receipt of supplemental oxygen and/or ventilatory support (CPAP or mechanical ventilation) at 36 weeks of postmenstrual age.

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*** p<0.001, ** p<0.01, * p<0.05