2.3. Template for Associate Member Registry Data Transmission

The forms below describes the data that should be sent to the Central Registry by associate registries (aggregate data) for a given birth year. The aggregate data should ideally be sent in a .csv file.

The following columns should be used in the .csv file for transmitting aggregate data. The file will be used by the Central Registry for importing the data in DMS.

- Centre
- Year
- anomalyId
- live
- still
- topfa
- live_ec
- still_ec
- topfa_ec
- completed_data

Centre Number:	
Denominator Data Year XXXX:	
Live births:	
Stillbirths:	
Total Births:	
Births (live and still) by Maternal Age:	
<20	
20-24	
25-29	
30-34	
35-39	
40-44	
45+	
Not known	

		Includes Chromosomal Cases				Excludes Chromosomal Cases			
		No of LB	**No of FD**	**No of TOPFA**	**Total cases**	**No of LB**	**No of FD**	**No of TOPFA**	**Total cases**
All Anomalies*									
Nervous system anomalies									
	Neural Tube Defects:								
	Anencephaly and similar								
	Encephalocele and meningocele								
	Spina Bifida								
	Hydrocephaly								
	Severe microcephaly								
	Arhinencephaly / holoprosencephaly								
	Agenesis of corpus callosum								
Eye anomalies									
	Anophthalmos / microphthalmos								
	Anophthalmos								
	Congenital cataract								
	Congenital glaucoma								
Ear, face and neck anomalies									
	Anotia and atresia / stenosis / stricture of external auditory canal								
Congenital Heart Defects (CHD)									
	Severe CHD								
	Common arterial truncus								
	Double outlet right ventricle								
	Double outlet left ventricle								

		Includes Chromosomal Cases				Excludes Chromosomal Cases			
		No of LB	**No of FD**	**No of TOPFA**	**Total cases**	**No of LB**	**No of FD**	**No of TOPFA**	**Total cases**
	Complete transposition of great arteries (D-TGA)								
	Single ventricle								
	Corrected transposition of great arteries (L-TGA)								
	Ventricular Septal Defect (VSD)								
	Atrial Septal Defect (ASD)								
	Atrioventricular Septal Defect (AVSD)								
	Tetralogy and pentalogy of Fallot								
	Triscuspid atresia and stenosis								
	Ebstein's anomaly								
	Pulmonary valve stenosis								
	Pulmonary valve atresia								
	Aortic valve atresia/stenosis								
	Mitral valve atresia/stenosis								
	Hypoplastic left heart (HLH/HLHS)								
	Hypoplastic right heart (HRH/HRHS)								
	Coarctation of aorta								
	Aortic atresia/interrupted aortic arch								
	Total anomalous pulmonary venous return								
	PDA as **only** CHD in term infants (LB and GA 37+ weeks)								
Respiratory anomalies									
	Choanal stenosis or atresia								

		Includes Chromosomal Cases				Excludes Chromosomal Cases			
		No of LB	**No of FD**	**No of TOPFA**	**Total cases**	**No of LB**	**No of FD**	**No of TOPFA**	**Total cases**
	Congenital pulmonary airway malformations (CPAM)								
Oro-facial clefts									
	Cleft lip with or without cleft palate								
	Cleft palate								
Gastro-intestinal anomalies									
	Oesophageal atresia with/without tracheo-oesophageal fistula								
	Duodenal atresia or stenosis								
	Atresia or stenosis of other parts of small intestine								
	Ano-rectal atresia and stenosis								
	Hirschsprung's disease								
	Atresia of bile ducts								
	Annular pancreas								
	Anomalies of intestinal fixation								
	Diaphragmatic hernia								
Abdominal wall defects									
	Gastroschisis								
	Omphalocele								
Congenital anomalies of kidney and urinary tract (CAKUT)									
	Unilateral renal agenesis								
	Bilateral renal agenesis including Potter syndrome								
	Multicystic renal dysplasia								
	Congenital hydronephrosis including ureter obstruction								

	Includes Chromosomal Cases				Excludes Chromosomal Cases			
	No of LB	**No of FD**	**No of TOPFA**	**Total cases**	**No of LB**	**No of FD**	**No of TOPFA**	**Total cases**
Lobulated, fused and horseshoe kidney and ectopic kidney								
Bladder exstrophy and / or epispadias								
Posterior urethral valve								
Prune belly syndrome								
Genital anomalies								
Hypospadias								
Indeterminate sex								
Limb anomalies								
Limb reduction defects (LRD)								
Transverse LRD								
Longitudinal preaxial LRD								
Longitudinal postaxial LRD								
Longitudinal central LRD								
Intercalary LRD								
Club foot - talipes equinovarus								
Hip dislocation								
Polydactyly								
Syndactyly								
Other anomalies/syndromes								
Craniosynostosis								
Congenital constriction bands/amniotic band sequence resulting in major malformations								
Situs inversus								
Conjoined twins								
VATER/VACTERL association								

	Includes Chromosomal Cases				Excludes Chromosomal Cases			
	No of LB	**No of FD**	**No of TOPFA**	**Total cases**	**No of LB**	**No of FD**	**No of TOPFA**	**Total cases**
Pierre-Robin sequence								
Caudal regression sequence								
Sirenomelia								
Septo-optic dysplasia								
Vascular disruption anomalies								
Laterality anomalies								
Teratogenic syndromes resulting in major malformations								
Valproate syndrome								
Maternal infections resulting in major malformations								
Genetic disorders *(genetic syndromes, hereditary skin disorders, skeletal dysplasias and chromosomal anomalies)*								
Skeletal dysplasias								
Down syndrome /trisomy 21								
Patau syndrome/trisomy 13								
Edwards syndrome/trisomy 18								
Turner syndrome								
Triploidy and polyploidy								

LB = Live births

FD = Fetal deaths / Still births from 20 weeks gestation

TOPFA = Termination of pregnancy for fetal anomaly following prenatal diagnosis

* All Anomalies = all cases with a major structural congenital anomaly, excluding cases with only minor anomalies as defined in Section 3.2 in Guide 1.5 for cases born post-2005. Cases with more than one anomaly are only counted once in the "All Anomalies" subgroup.