

Item number	Item	Code	Definition
Demographic data			
1	Clinic ID	free text	
2	Patient ID	center specific	
3	Date of birth	dd.mm.yyyy	
4	Gender	1 male 2 female	
Basic morphology			
			morphology prior to first operation
5	Heart position	1 left 2 right 3 median	
6	Atrial situs	1 usual 2 mirror imagagery 3 left isomerism 4 right isomerism	
7	Atrioventricular alignment	1 concordant 2 discordant 3 double inlet left ventricle 4 double inlet right ventricle	
8	Ventriculoarterial alignment	1 concordant 2 discordant 3 double outlet left ventricle 4 double outlet right ventricle	
9	Position of the great arteries	1 aorta left 2 aorta right 3 aorta anterior	
10	Functional single ventricle	1 yes 0 no	
11	Type of ventricular septal defect	factor_code from Diagnosis, 0 if absent	
12	Type of pulmonary outflow tract obstruction	factor_code from Diagnosis, 0 if absent	
13	Type of systemic outflow tract obstruction	factor_code from Diagnosis, 0 if absent	
14	Type of tricuspid valve pathology	factor_code from Diagnosis, 0 if absent	
15	Type of mitral valve pathology	factor_code from Diagnosis, 0 if absent	
16-20	Type of other pathology 0-5	factor_code from Diagnosis, 0 if absent	
21	further Type of other pathology	factor_code from Diagnosis, multiple codes in one field with spaces	
Prior palliative procedures and interventions			
22	Number of palliative operations	number	
23-27	Date of 0 to 5 palliative operation	dd.mm.yyyy	
28-32	Type of 0 to 5 palliative operation	factor_code from Procedures	
33	further palliative operations	date and type factor_code from Procedures, 0 if absent	
34	Number of palliative interventions	number	
35-37	Date of 0 to 3 palliative interventions	dd.mm.yyyy	
38-40	Type of 0 to 3 palliative interventions	free text	
41	further palliative interventions	date and type free text	
Index operation			
42	Date of index operation	dd.mm.yyyy	
43	Weight	Kg, 1 decimal	at the time of index operation
44	Hight	cm	at the time of index operation
45-49	Clinical and extracardiac factors 0 to 5	factor_code from Clinical and extracardiac, 0 if absent	at hospital admission prior to index operation
50-54	Preoperative risk factors 0 to 5	factor_code from Preoperative risk factors, 0 if absent	at hospital admission prior to index operation
55	Preoperative NYHA class	I-IV	at hospital admission prior to index operation
56	Preoperative systemic ventricular function	1 normal or mildly impaired 2 moderately impaired 3 severely impaired	
57	Preoperative pulmonary ventricular function	1 normal or mildly impaired 2 moderately impaired 3 severely impaired	
58	Preoperative pulmonary outflow tract obstruction	1 absent or mild 2 moderate 3 severe	<30mmHg mean 30-60mmHg mean >60mmHg mean
59	Preoperative systemic outflow tract obstruction	1 absent or mild 2 moderate 3 severe	<30mmHg mean 30-60mmHg mean >60mmHg mean
60	Preoperative tricuspid valve regurgitation	1 absent or mild 2 moderate 3 severe	
61	Preoperative mitral valve pathology	1 absent or mild 2 moderate 3 severe	
62	Preoperative VSD pathology	0 no VSD 1 restrictive VSD 2 unrestrictive VSD	
63	Straddling AV valve	0 no straddling 1 straddling	
64	Indication for index operation	1 tricuspid regurgitation 2 excessive pulmonary blood flow 3 insufficient pulmonary blood flow 4 single ventricle palliation 5 other	
65	Other indication for index operation	free text	
66	Type of index operation	factor_code from Procedures	
67	Type of conduit	0 no conduit 1 allograft pulmonary 2 allograft aortic 3 xenograft 4 mechanical prostheses 5 monocusp 6 valveless	
68-71	Type of additional procedures 0 to 3	factor_code from Procedures, 0 if absent	

72 further	Type of additional procedures	factor_code from Procedures multiple codes in one field with spaces	
73	Time on extracorporeal circulation	Minutes	
74	Ischemic time	Minutes	
75-78	Complications 0 to 5	factor_code from Complications, 0 if absent	prior to hospital discharge after index operation
79 further	Complications	factor_code from Complications, multiple codes in one field with spaces	

Reoperations and reinterventions

80	Number of reoperations	number	
81-85	Date of 0 to 5 reoperation	dd.mm.yyyy	
86-90	Type of 0 to 5 reoperation	factor_code from Procedures, 0 if absent	
91 further	reoperations	factor_code from Procedures multiple codes in one field with spaces	
92	Number of reinterventions	number	
93-95	Date of 0 to 3 reinterventions	dd.mm.yyyy	
96-98	Type of 0 to 3 reinterventions	free text	
99 further	reoperations	date and type free text	

Final follow up

100	Date of final follow up	dd.mm.yyyy	date of last follow up or date of death
101	Status	0 alive 1 dead	
102	cause of death	free text	
103	Systemic ventricular function	1 normal or mildly impaired 2 moderately impaired 3 severely impaired	
104	Pulmonary ventricular function	1 normal or mildly impaired 2 moderately impaired 3 severely impaired	
105	Pulmonary outflow tract obstruction	1 absent or mild 2 moderate 3 severe	<30mmHg mean 30-60mmHg mean >60mmHg mean
106	Systemic outflow tract obstruction	1 absent or mild 2 moderate 3 severe	<30mmHg mean 30-60mmHg mean >60mmHg mean
107	Tricuspid valve regurgitation	1 absent or mild 2 moderate 3 severe	
108	Mitral valve pathology	1 absent or mild 2 moderate 3 severe	
109-113	Type of other pathology at fu 0 to 5	factor_code from Diagnosis, 0 if absent	
114 further	Type of other pathology at fu	factor_code from Diagnosis, multiple codes in one field with spaces	
115	Cardiac rhythm	1 Sinus rhythm 2 No sinus rhythm no pacemaker 3 Pacemaker rhythm	
116	Infective endocarditis	1 yes 0 no	
117	thrombosis	1 yes 0 no	
118	embolism	1 yes 0 no	
119	bleeding	1 yes 0 no	