Appendix I

GUIDANCE FOR COMPLETION OF FORMS FOR THE UNITED KINGDOM CARDIAC SURGICAL REGISTER

1. Returns should be made from individual surgical units and contain comprehensive figures for all work done in that unit. Where surgeons work in more than one hospital their results will be entered in separate returns from each hospital

2. Each form is divided into the following sections:
    1. Unit name and details (1 page)
    2. Surgery for acquired heart disease (4 pages)
        - Surgery for acquired valve disease
        - Surgery for ischaemic heart disease
        - Miscellaneous procedures for acquired heart disease
    3. Congenital Surgery (3 pages)
        - Extracardiac lesions
        - Congenital valve surgery
        - Defects of partitioning
        - Miscellaneous procedures for acquired heart disease

3. Combined valve and coronary procedures should be entered under, "Surgery for Acquired Valve Disease". ALL other coronary operations should be entered in the section: "Surgery for ischaemic heart disease".

4. No operation should be entered more than once. When in doubt include it under what is considered the major procedure. If still in doubt, or if no appropriate category is apparent, enter into spaces entitled "Other", or list on a separate sheet of paper.

5. C.P.B. refers to any operation during which cardiopulmonary bypass was used at some stage of the procedure.

6. Mortality. On all forms D = death and relates to 30 day postoperative mortality.

7. Under "Congenital Surgery" it is not necessary to specify the type of palliative procedure performed.

Appendix II

Paediatric Cardiac Surgical Data

Self-completion Questionnaire

Please tick one box for each statement.

IMPORTANT**: The statements refer to **the unit and period for which you collected statistics for the UK Cardiac Surgical Register.

	Strongly agree	Agree	Don't know	Disagree	Strongly disagree
1. There is / was very little missing data on number of diagnoses/procedures.	☐	☐	☐	☐	☐
2. There is / was very little missing data on deaths.	☐	☐	☐	☐	☐
3. The number of procedures performed is / was broadly accurate.	☐	☐	☐	☐	☐
4. There is / was under-reporting of deaths.	☐	☐	☐	☐	☐
5. There is / was double-counting of deaths.	☐	☐	☐	☐	☐
6. The mortality figures are broadly accurate.	☐	☐	☐	☐	☐
7. The register is more accurate in terms of procedures than HES/PAS*.	☐	☐	☐	☐	☐
8. The register is more accurate in terms of deaths than HES/PAS*.	☐	☐	☐	☐	☐

* Hospital Episode Statistics - National system for recording information on all in-patients in England.
Patient Administration System : local computerised record system

Your answers will remain anonymous

Thank you for your co-operation in this exercise.

Appendix III SURGERY FOR CONGENITAL HEART DISEASE 1995 CONGENTIAL - 1

N.B. Each operation must be entered once only in the category of what is considered to be the major procedure.

	Over 1 Year				Under 1 Year			
	Closed		Open		Closed		Open	
	No.	D.	No.	D.	No.	D.	No.	D.
EXTRACARDIAC LESIONS								
Persistent ductus arteriosus								
A-P window								
Coarctation of aorta - simple								
- complicated (plus other major defect)								
Interrupted Aortic Arch								
Vascular Ring								
CONGENITAL VALVE SURGERY								
Aortic (exclude adult calcific disease)								
- stenosis - valvotomy								
- regurgitation - repair								
- subvalvar stenosis - repair								
- supravalvar stenosis - repair								
- replacement (homograft)								
(xenograft)								
(prosthesis)								
Pulmonary - stenosis - valvotomy								
- regurgitation - repair								
- RVOT obstruction - repair								
- replacement (homograft)								
(xenograft)								
(prosthesis)								
Mitral - stenosis - valvotomy								
- regurgitation - repair								
- replacement (homograft)								
(xenograft)								
(prosthesis)								
Other (please specify)								
TOTAL CONGENITAL PAGE 1								

DEFECTS OF PARTITIONING	Over 1 Year				Under 1 Year			
	Closed		Open		Closed		Open	
	No.	D.	No.	D.	No.	D.	No.	D.
Atrial septal defect (Secundum or Sinus Venosus)								
Partial A-V Canal (Primum ASD)								
Common (single) atrium								
Complete A-V Canal								
(palliative procedure								
(corrective procedure								
Ventricular septal defect (with or without ASD)								
(palliative procedure								
(corrective procedure								
Double outlet RV								
(palliative procedure								
(corrective procedure								
Double outlet RV and PS								
(palliative procedure								
(corrective procedure								
Truncus arteriosus								
(palliative procedure								
(corrective procedure								
TGA with intact ventricular septum								
(palliative procedure								
(corrective procedure								
TGA with VSD								
(palliative procedure								
(corrective procedure								
TGA with VSD and PS								
(palliative procedure								
(corrective procedure								
TGA with other significant anomaly								
(palliative procedure								
(corrective procedure								
Corrected TGA and VSD								
(palliative procedure								
(corrective procedure								
Corrected TGA and other significant anomaly								
(palliative procedure								
(corrective procedure								
Single ventricle								
(palliative procedure								
(septation procedure								
(Fontan-type procedure								
TOTAL CONGENITAL PAGE 2								

	Over 1 Year				Under 1 Year			
	Closed		Open		Closed		Open	
	No.	D.	No.	D.	No.	D.	No.	D.
Tetralogy of Fallot								
(palliative procedure								
(corrective procedure								
VSD and PS (Valve or Sub-valve)								
(palliative procedure								
(corrective procedure								
Pulmonary atresia with VSD								
(palliative procedure								
(corrective procedure								
Pulmonary atresia with intact septum								
(palliative procedure								
(corrective procedure								
Tricuspid atresia								
(palliative procedure								
(corrective procedure								
Ebstein's anomaly								
(palliative procedure								
(corrective procedure								
MISCELLANEOUS								
Total anomalous pulmonary venous return								
Cor Triatriatum								
Anomalous origin coronary artery								
Coronary artery fistula								
Exploration only								
Surgical procedures for other conditions (please specify)								
TOTAL CONGENITAL PAGE 3								
TOTAL CONGENITAL PAGE 2								
TOTAL CONGENITAL PAGE 1								
TOTAL CONGENITAL OPERATIONS								

Appendix IV

Figure 7 **OPEN CONGENITAL HEART OPERATIONS 1994/5**

VALVE OPERATIONS		UNDER 1 YEAR			1 to 15 YEARS			16 YEARS plus			TOTAL		
		N	died	%	N	died	%	N	died	%	N	died	%
AORTIC													
	stenosis valvotomy	22	4	18	12	0	0	9	0	0	43	4	9.3
	regurgitation repair	2	0	0	3	0	0	1	0	0	6	0	0
	subvalvar stenosis repair	3	1	33	32	0	0	6	0	0	41	1	2.4
	supravalvar stenosis repair	1	1	100	13	0	0	0	0	-	14	1	7.1
	replacement - homograft	0	0	-	13	0	0	3	0	0	16	0	0
	-bioprosthesis	0	0	-	0	0	-	5	0	0	5	0	0
	-mechanical valve	1	0	0	13	0	0	59	1	1.7	73	1	1.4
	-autograft	3	0	0	3	0	0	1	0	0	7	0	0
AORTIC TOTAL		**32**	**6**	**19**	**89**	**0**	**0**	**84**	**1**	**1.2**	**205**	**7**	**3.4**
PULMONARY													
	stenosis valvotomy	9	0	0	4	0	0	2	0	0	15	0	0
	regurgitation repair	0	0	-	0	0	-	0	0	-	0	0	-
	RVOT obstruction - repair	8	1	13	6	0	0	3	0	0	17	1	5.9
	replacement - homograft	0	0	-	10	0	0	4	0	0	14	0	0
	-bioprosthesis	0	0	-	1	0	0	0	0	-	1	0	0
	-mechanical valve	0	0	-	1	0	0	0	0	-	1	0	0
PULMONARY TOTAL		**17**	**1**	**5.9**	**22**	**0**	**0**	**9**	**0**	**0**	**48**	**1**	**2.1**
MITRAL													
	stenosis valvotomy	0	0	-	0	0	-	2	0	0	2	0	0
	regurgitation repair	10	0	0	15	0	0	4	0	0	29	0	0
	replacement - homograft	0	0	-	0	0	-	0	0	-	0	0	-
	-bioprosthesis	0	0	-	1	0	0	2	0	0	3	0	0
	-mechanical valve	3	1	33	12	0	0	2	0	0	17	1	5.9
MITRAL TOTAL		**13**	**1**	**7.7**	**28**	**0**	**0**	**10**	**0**	**0**	**51**	**1**	**2**
Other valve operations		5	3	60	21	2	9.5	7	0	0	33	5	15
TOTAL OPEN VALVE		**67**	**11**	**16**	**160**	**2**	**1.3**	**110**	**1**	**0.9**	**337**	**14**	**4.2**

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Appendix IV (contd.)

Figure 8 **OPEN CONGENITAL HEART OPERATIONS 1994/5**

PARTITIONING & OTHER DEFECTS		UNDER 1 YEAR N	died	%	1 to 15 YEARS N	died	%	16 YEARS plus N	died	%	TOTAL N	died	%
Atrial septal defect		40	0	0	247	1	0.4	197	1	0.5	484	2	0.4
Partial A-V canal		15	1	6.7	45	0	0	13	0	0	73	1	1.4
Common single atrium		3	1	33	2	0	0	0	0	-	5	1	20
Complete A-V canal	-palliative	22	4	18	4	0	0	0	0	-	26	4	15
	-corrective	92	11	12	32	3	9.4	0	0	-	124	14	11
VSD +/- ASD	-palliative	2	1	50	0	0	-	6	1	17	8	2	25
	-corrective	195	4	2.1	59	0	0	8	1	13	262	5	1.9
Double outlet RV	-palliative	3	0	0	6	2	33	1	0	0	10	2	20
	-corrective	9	1	11	13	4	31	0	0	-	22	5	23
Double outlet RV & PS	-palliative	3	2	67	2	0	0	0	0	-	5	2	40
	-corrective	2	0	0	13	2	15	0	0	-	15	2	13
Truncus arteriosus	-palliative	3	2	67	0	0	-	0	0	-	3	2	67
	-corrective	21	7	33	4	1	25	0	0	-	25	8	32
TGA with intact septum	-palliative	5	1	20	1	0	0	0	0	-	6	1	17
	-corrective	114	8	7	7	1	14	0	0	-	121	9	7.4
TGA with VSD	-palliative	6	2	33	4	0	0	0	0	-	10	2	20
	-corrective	32	4	13	6	0	0	1	1	100	39	5	13
TGA with VSD & PS	-palliative	0	0	-	1	0	0	0	0	-	1	0	0
	-corrective	5	3	60	7	1	14	1	0	0	13	4	31
TGA & other anomolies	-palliative	6	3	50	1	0	0	0	0	-	7	3	43
	-corrective	11	1	9.1	7	1	14	1	0	0	19	2	11
Corrected TGA & VSD	-palliative	0	0	-	0	0	-	0	0	-	0	0	-
	-corrective	1	0	0	5	1	20	2	1	50	8	2	25
Corrected TGA & other	-palliative	3	0	0	0	0	-	0	0	-	3	0	0
	-corrective	1	0	0	7	0	0	0	0	-	8	0	0
Single ventricle	-palliative	25	11	44	22	0	0	1	0	0	48	11	23
	-septation	0	0	-	0	0	-	1	0	0	1	0	0
	-Fontan-type	13	4	31	55	4	7.3	4	1	25	72	9	13
TOTAL PARTITIONING etc		**632**	**71**	**11**	**550**	**21**	**3.8**	**236**	**6**	**2.5**	**1418**	**98**	**6.9**

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Appendix IV (contd.)

Figure 9 **OPEN CONGENITAL HEART OPERATIONS 1994/5**

RIGHT SIDED LESIONS & MISCELLANEOUS		UNDER 1 YEAR N	died	%	1 to 15 YEARS N	died	%	16 YEARS plus N	died	%	TOTAL N	died	%
Fallot's Tetralogy	-palliative	8	0	0	2	0	0	0	0	-	10	0	0
	-corrective	40	6	15	133	7	5.3	17	2	12	190	15	7.9
VSD +/- PS	-palliative	3	0	0	4	0	0	0	0	-	7	0	0
(valve or sub valve)	-corrective	29	3	10	31	0	0	6	1	17	66	4	6.1
Pulm. atresia with VSD	-palliative	1	0	0	5	0	0	0	0	-	6	0	0
	-corrective	14	0	0	31	4	13	3	1	33	48	5	10
Tricuspid atresia	-palliative	2	0	0	10	0	0	0	0	-	12	0	0
	-Fontan	2	0	0	20	2	10	0	0	-	22	2	9.1
Truncus arteriosus	-palliative	7	1	14	1	1	100	0	0	-	8	2	25
	-corrective	15	3	20	1	0	0	0	0	-	16	3	19
Ebstein's anomoly	-palliative	0	0	-	1	0	0	1	0	0	2	0	0
	-corrective	4	1	25	2	1	50	3	0	0	9	2	22
MISCELLANEOUS													
Total anomolous pulm. venous drainage		50	6	12	5	0	0	0	0	-	55	6	11
Cor triatriatum		1	0	0	5	0	0	1	0	0	7	0	0
Anomolous origin coronary artery		11	2	18	2	1	50	0	0	-	13	3	23
Coronary artery fistula		0	0	-	2	0	0	1	0	0	3	0	0
Exploration only		0	0	-	3	0	0	1	0	0	4	0	0
Other		86	16	19	40	3	7.5	10	0	0	136	19	14
TOTAL R SIDED & MISC.		**273**	**38**	**14**	**298**	**19**	**6.4**	**43**	**4**	**9.3**	**614**	**61**	**9.9**
TOTAL VALVES (figure 7)		67	11	16	160	2	1.3	110	1	0.9	337	14	4.2
TOTAL PART. & DEFECTS (figure 8)		632	71	11	550	21	3.8	236	6	2.5	1418	98	6.9
EXTRACARDIAC		39	5	13	6	0	0	7	0	0	52	5	9.6
TOTAL OPEN CONGENITAL		**1011**	**125**	**12**	**1014**	**42**	**4.1**	**396**	**11**	**2.8**	**2421**	**178**	**7.4**

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