Appendix I

Methodology of data handling for UKCSR returns

Background

The Inquiry obtained copies of all returns made to the Society covering the years 1977 to 1996/7, with the exception of those for 1983, which were illegible due to being recorded on faded fax paper.

Preliminary checks of the forms for coverage and legibility had already been undertaken by the Inquiry and some queries raised with the Society.[1]

Copies of the forms and any relevant documents were delivered to Professor Murray for the analysis.

Methodology

Each form was allocated a unique identifier, starting from 1 for the first form of 1977 through to 816 for the last form of 1996/7.

A database was then set up in Microsoft Excel and the centre and year identifiers were entered along with the total congenital operation figures for each form.

A second database was set up in Microsoft Access into which the figures for individual congenital operations were entered, but only for the years 1984 to 1995/6 and for the centres relevant to the Inquiry's analysis.

Centres were allocated new codes by the Inquiry as follows:

Synthesis of Statistical Sources: Provider Anonymity Codes

UKCSR Code	New (Inquiry)Code
5	3
6	9
21 + 40	5
17	10
23	7
25	12
26 + 60 + 70	1
28	6
29	4
30	2
35	8
45	11

[Note: No data were received for centres 60 or 70.]

Database set-up and data entry were performed by an experienced data manager known to have a good record of accuracy.

Data available

Forms were made available to the Inquiry by the Society's agent, who had stored them at his home. He is confident that all forms were available and forwarded, with the exception of the forms for 1983, as already noted (personal communication).

Data entry checks

A random sample of 10% of forms were independently checked against the entries in the database. This showed an entry error rate of less than 0.5% (4 out of 814 fields checked contained an error).

Once all forms were entered, statistical checks were run on the database to identify outliers, duplicates, and missing values to see if these were attributable to data entry error.
The checks consisted of summary statistics, histograms and plots of numbers of procedures against related deaths.

Comparison of database with Society's reported figures

Table I.1 compares figures published by the Society (Report) and corresponding figures produced from our database of forms (Forms).

There is generally very good agreement.

Figures which differ markedly are:

1. The % deaths in the over ones for 1986.
   The number of procedures is similar (1511 against 1496), but our database has more deaths recorded (8.6% against 7.4%).
2. Numbers of procedures for 1990, in both age groups.
   Here our figures are higher then the Society's (1865 against 1750 in the over-ones, 815 against 770 in the under ones). While this resulted in minimal increase in the % deaths in the over ones (4.3% against 4.2%), there was a large difference in the % deaths in the under ones (16.4% against 15.8%).
3. All figures for 1993/4 were discrepant, with both the numbers of procedures and % death being higher in the society's figures for the over ones (1599 against 1347; 5.4 against 5.0), and the number of procedures higher in the under ones (1006 against 772) but the death rate lower (10.5% against 11.0%).
4. The pattern for 1994/5 was similar to 1993/4, except that the number of procedures in the under ones was not greatly different, although all other figures did differ markedly (1410 against 1308; 3.8% against 3.4%, 12.0% against 12.3%) .

Table I.1

Comparison of register reported figures and reconstructed database from procedures on forms

Open congenital heart surgery

	Over One Year				*Under One Year*			
	Number of procedures		*% Deaths*		*Number of procedures*		*% Deaths*	
Source	Report	*Forms*	Report	*Forms*	Report	*Forms*	Report	*Forms*
Year								
1985	1575	*1580*	7.2	*7.2*	469	*474*	21.7	*21.9*
1986	1511	*1496*	7.4	*8.6*	581	*581*	21.2	*21.2*
1987	1660	*1662*	6.6	*6.6*	588	*586*	23.5	*23.5*
1988	1642	*1623*	6.9	*6.8*	708	*704*	19.0	*18.9*
1989	1605	*1613*	7.5	*7.6*	727	*727*	20.4	*20.4*
1990	1750	*1865*	4.2	*4.3*	770	*815*	15.8	*16.4*
1991	1788	*1821*	5.6	*5.5*	926	*914*	16.5	*16.5*
1992	1874	*1840*	5.4	*5.3*	1137	*1105*	14.0	*13.8*
1993/4	1599	*1347*	5.4	*5.0*	1006	*772*	10.5	*11.0*
1994/5	1410	*1308*	3.8	*3.4*	1011	*972*	12.0	*12.3*
1995/6	1852	*1848*	3.3	*3.2*	1285	*1285*	12.1	*12.2*
1996/7	1507	*1475*	3.5	*3.9*	1153	*1156*	7.5	*7.5*

Notes:

1. Number of procedures : figures in red indicate difference of more than 5%
2. % Deaths : figures in red indicate difference of more than 0.2%