A report on local data relating to children who received cardiac surgery under the terms of reference of the Bristol Royal Infirmary Inquiry

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EXECUTIVE SUMMARY

1. This report summarises data from computer records derived from three sources of data relating to care that children received during the time period specified in the terms of reference of the Bristol Royal Infirmary Inquiry. The first source is the Patient Administration System (PAS) of the United Bristol Healthcare NHS Trust (UBHT). The second is the medical record notes supplied to the Inquiry by the UBHT. A summary of each child's medical records has been created specifically for the Inquiry and entered on to computer as the clinical coded records (CCR). The third source is the logs from the two consultant cardiac surgeons responsible for most of the work during the period of relevance to the Inquiry (Surgeons' Logs – SL).

2. The operative procedures identified from each source have been classified using internationally agreed codes. They have been further categorised into thirteen specific types of operation, similar to those used for summaries by cardiac surgeons in the UK, and by whether the operation was "open-heart", involving cardio-pulmonary bypass, or "closed-heart".

3. The PAS is limited to the years 1988 onwards. The CCR and SL cover all years (1984-1995) and the full range of surgery at both Bristol hospitals, but the SL does not cover the "closed-heart" operations done at the Bristol Royal Hospital for Sick Children (BRHSC).

4. The main result of the operation that is available in all three sources is whether the child died within 30 days of the operation. The numbers of deaths and the death rate have been calculated for the different groups of operative procedures.

5. The classification of operative procedures has been done separately, and by different people, for each of the three sources. Given that there will be inevitable

variation in the way that the classification has been done, the overall results show considerable similarity between the three different sources when comparisons are restricted to similar time periods.

6. The death rate has been based on deaths occurring within thirty days of an operation, and is seen to be about 11% overall, though for the open heart surgery it is rather higher. Each of the sources indicates high death rates for arterial switch operations and truncus arteriosus. The rates for atrial ventricular septal defect (AVSD) operations are higher than average but are not as high as for truncus and switch operations. Each of the sources shows slightly higher rates from 1988 to the end of 1990 and much lower rates in the later part of 1995.

7. Each of the sources shows higher death rates in the first year of life than subsequently.

8. The overall conclusion is that the pattern of results is similar in the three sources where direct comparison is sensible. This is both for the numbers of operations and for the death rate, though where numbers in any particular category are small there is an absence of perfect agreement. It is clear that none of the sources, viewed one at a time, is adequate to be sure about the details of operations. However, taken together, the results are consistent and there are no startling discrepancies between the three sources.

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Annex 1:

Schematic representation of the data on children, admissions, operations and operative procedures.

1 INTRODUCTION

1.1 This report provides a summary of the data from three local sources available to the Inquiry. The terms of reference of the Inquiry are such that it is important to examine what had happened to all the children who received complex cardiac surgery in Bristol. In March 1999, the Inquiry Secretariat published a document on "Making Use of Relevant Data Sources". This gave a brief description of data available both nationally and locally. A "Preliminary Overview of Existing data Sources relevant to the Inquiry's remit" was published in July 1999 as INQ 0001. A further note was published in August 1999 entitled "The Inquiry's Approach to the Assessment of the Adequacy of Paediatric Cardiac Surgical Services".

1.2 About two thousand sets of clinical records were supplied to the Inquiry by the United Bristol Healthcare Trust (UBHT). These medical records formed a very large volume of data on paper. The Inquiry Panel decided to produce a structured summary of each patient's set of clinical notes from the large number of paper records. This summary has been entered on to computer as a main source of data. The main method for identifying the children who were receiving cardiac surgery was to scan the logs from the two surgeons who had carried out most of the surgery during the period of interest to the Inquiry. These logs themselves were also submitted to the Inquiry and are a second local source of data. It was clear that the UBHT Patient Administration System (PAS) also had data, originally collected for administrative purposes, which would be useful to the Inquiry. This is a third source and was used by the UBHT as an additional way of identifying medical records to be supplied to the Inquiry. About 80 extra records were identified as a result of searching the PAS. Mr Gray has given a description of this process in evidence to the Inquiry {Submission dated 30 April 1999, *WIT 0137*}.

1.3 The structured summary of the clinical records for each patient used an internationally recognised method for classification of the diagnosis and

operations carried out (International Classification of Diseases – ICD). The outcome in terms of whether the child was still alive or not at the last date available from the hospital records was also recorded. The data from this summary were entered into a computer and called the Clinically Coded Records (CCR) Database.

1.4 This report describes each of these sets of data in more detail and provides some analyses. Although the hospital medical records were available in paper form, the first set of computer records that became available was from the PAS; the second was the CCR and the third, the Surgeons' logs (SL). The sources are discussed in this order, and all the results in this report are based on computer records.

2 THE BRISTOL CONTEXT

2.1 Bristol, in common with other hospitals within the National Health Service (NHS), is required to provide summary data on episodes of care for patients. It does this using the local computer-based Patient Administration System (PAS) for providing national returns to the NHS, known as Hospital Episode Statistics (HES). Most other Health Care Trusts in England and Wales have similar systems for producing these returns. More details on the national picture derived from HES are given in a separate report {Aylin *et al* 1999}. The Bristol PAS is a fairly comprehensive computer system developed from a long tradition of using computers for patient administration in the Bristol area that was begun in the late 1960's. Neither in Bristol nor elsewhere have patient administration systems generally been used for looking at clinical outcomes in a rigorous way. In most instances the recording of death is limited to those deaths which occur prior to discharge from hospital. The Bristol system has included patient outcome, in terms of death, for at least some patients beyond the period when a patient was actually in hospital. This is unusual and allows for a more comprehensive picture of the vital status of patients than is usually the case for administration-based

systems.

2.2 In Bristol, as elsewhere, the use of a log by a cardiac surgeon was an individual decision and not one that was required or necessarily encouraged by the hospital administration. The cardiac log scheme was begun by Mr Wisheart and used by him for the whole period he was operating. He has described this in evidence to the Inquiry {*WIT 0120 0256- 0262*}. The method was also used by Mr Dhasmana, and he has confirmed this in evidence {*WIT 0084, 0001-0005*}. These logs were hand-written but have been transcribed on to computer coding forms and entered on to a computer database specifically for the Inquiry.

2.3 Medical records of patients and their treatment are kept by every hospital, usually in paper form, with hand-written and (occasionally) typed notes from health care staff. Their purpose is to record the immediate clinical care of patients. They are not generally designed for research purposes. Bristol was no different from other hospitals in this respect. Research on particular diseases using medical records is, nevertheless, a common activity. A specific project may be set up to record, for example, data such as prescriptions of drugs.

2.4 Phase 1 of the Inquiry is examining "the delivery of complex paediatric cardiac surgical services at the Bristol Royal Infirmary and Children's Hospital from 1984 to 1995". The "Issues List" published by the Inquiry on 22 February 1999 sets out 14 major topics (A to N) with the aim "to examine the whole system responsible for the management of children needing heart surgery services." This report largely relates to issue C: "The Service Provided: Nature and Outcomes". It will have some sections that will be relevant to other issues such as D: "Referrals" and M: "Review of cases and Medical and Clinical Audit".

3 Description and statistical review of the sources of data

General principles

3.1 The Inquiry overview noted in paragraph 1.1 of the Introduction lists six sources of data; the first two are national, and this report relates to three of the others. Any source of data will have limitations, and it must be remembered that its limitations, strengths and weaknesses must be judged in the light of the purpose for which it was set up. The Inquiry is particularly interested in the quality of the whole system of care that the relevant children received, in order to come to a view on the adequacy of this system. None of the sources of data was set up with this objective. Each of them can contribute to the realisation of the objective, but the extent to which they can do so is variable.

3.2 Children who were admitted to the Bristol Royal Infirmary (BRI) for heart surgery would be admitted there only for "open" heart surgery. This involves having cardiopulmonary by-pass. "Closed" heart operations could be done at the Bristol Royal Hospital for Sick Children (BRHSC).

3.3 It must also be acknowledged that whenever data are collected which relate to a feature that shows variability, such as mortality rate, this is subject to statistical fluctuation. When dealing with small amounts of data this fluctuation leads to considerable uncertainty in determining the true rate. The uncertainty decreases as the amount of data increases. Statistical analysis is able to help make judgements about whether an apparent difference in rates could easily be due to chance variation or not.

3.4 It is most important to realise that when apparently precise figures are presented as percentages, they will probably have a spurious precision. This is the way the world is – it is not a feature that applies to the data from this Inquiry alone. If a coin is tossed 100 times, it will not necessarily come up "heads" exactly 50 times,

even though we are sure that, if it is an ordinary coin, it should have a 50% chance of being "heads". We could reasonably easily get as few as 40 or as many as 60 "heads", but it would be rare to get more extreme values like 30 or 70 "heads". It is clear that if we were, not knowing what the true percentage is, to get something happening (such as deaths after an operation) 40 times out of 100, then the true percentage could be 50%. Likewise, if it happens 50 times out of 100, there is still uncertainty about the true percentage – it could reasonably easily be anywhere between 40% and 60%. If the coin were tossed only 10 times, then getting 2 "heads" or 8 "heads" (20% or 80%) would not be that unlikely. The uncertainty in percentage terms is greater when the number of times the coin is tossed is smaller. Statistical methods exist to quantify the uncertainty. These methods can be used to see when caution must be exercised in emphasising a difference in percentages, and when a difference is sufficiently large that statistical fluctuation is not a likely explanation of the difference.

Problems of comparisons

3.5 Even when the statistical uncertainty is small, more fundamental problems occur when attempting to make comparisons. If one centre is to be compared with another, the children treated will not necessarily be similar in each centre. Differences found may be due to the characteristics of the children rather than in the effect of the centres. Similar arguments apply to comparing individual surgeons. When comparing new drug treatments, it is usually regarded as imperative that groups which are compared are made as similar as possible. This is done by *randomly allocating* patients to the treatments. This is known as a *randomised controlled trial*. Such trials do occur in surgery though less frequently than in comparisons of new medicines.

3.6 Randomised trials are not used to compare individual surgeons or centres (they would be impractical). The consequence is that the groups to be compared may differ in the outcomes, even when this is nothing to do with the treatment given by the centre or surgeon. Attempts may be made to allow for factors which affect prognosis, but any such allowance is inevitably less than perfect. The statistical methods themselves for adjusting for prognostic factors cannot be perfect. It is also possible that important prognostic factors that differ between the groups have not been measured. Comparisons must be treated with caution. Overall scientific judgement includes more than just the statistical arithmetic.

3.7 In the consideration of uncertainty, a further problem arises because our counting system is imperfect. We may not have exactly the same numbers of operations and deaths when we compare two ways of doing the counting. It is very helpful to have different methods when each is subject to error, since concordance between them can increase confidence that our conclusions are valid.

Statistical Review of the Patient Administration System (PAS)

3.8 There have been computer systems for processing information about patients in hospitals in the Bristol area since 1964. In this computer system, details are recorded on each in-patient in one of the hospitals in the UBHT. It tracks, in outline fashion, what has happened to each patient. It has several purposes:

a) For returns to be made of hospital activity to the Department of Health.
b) To allow smooth administration of the hospital. With the advent of the internal market where providers of care, such as hospitals, are separated from those who pay for the care (described as "purchasers") it meets the need for administration to keep track of these activities in greater detail.
c) It may also be used for purposes of planning changes to the balance of activity in the future.

3.9 The data largely relate to the short-term activity during each episode of care. When a patient is admitted to a hospital, it is always under the care of a named hospital consultant. On some occasions, during a single admission, a patient may be transferred to the care of a different consultant. Each such "episode" of care under a consultant forms a unit to which the PAS system refers. Demographic information, address details, date of birth (& age), sex, hospital record number etc. form the basic data. A record of the diagnoses, any operations with dates, dates of admission and discharge is built up during the stay in hospital. Information on clinical outcome is very limited, but death, if it occurs, is recorded with the date of death where this is known. Information on death occurring outside hospital is entered after discharge in at least some instances.

3.10 The purpose of the system is not to store information that a doctor requires to care for the patient, nor is it intended for audit of the quality of care. Any such use must take account of the likelihood that important details may not be recorded.

3.11 The data on diagnoses and operations are derived from examination of discharge letters written when the patient leaves the hospital, and from the case notes written by the doctors. Administrative clerks trained in medical terminology scan the available information and summarise it using codes describing the diagnosis and operation. This task is needed, and carried out, on a worldwide basis. To simplify recording of diagnoses and to facilitate international comparisons of the amount and rate of occurrence of disease, the World Health Organisation (WHO) has published a dictionary of terms with corresponding numerical codes called the International Classification of Diseases (ICD). This classification has been revised and extended on several occasions reflecting increased knowledge and diagnostic techniques. The latest revision in common use is the tenth (ICD-10), though the ninth revision (ICD-9) was in use for much of the period covered by the Inquiry. UK liaison with WHO regarding ICD is co-ordinated by the Office for National Statistics (ONS), formerly the Office of Population, Censuses and Surveys (OPCS).

3.12 Operations do not have the same degree of international concurrence in their description. It is the usual practice in UK hospitals to use a list of operations maintained by ONS (OPCS in the past). This also has a code (a letter and a number) to describe each operative procedure.

3.13 The administrative clerks (known as "coders") who classify diagnoses and operations for the PAS are not medically qualified, and they may misunderstand the medical information in the medical records of patients. The medical records themselves may not be clear in describing the diagnoses or operations for every patient. The ICD coding system may also have inadequacies when used in a very specialised area. Individual coders vary in their experience, but there are some highly experienced coders who are very good at carrying out the classification of diagnosis and operation.

3.14 The terms of reference of the Inquiry include children seen at Bristol between 1984 and 1995. The PAS has data only from 1st January 1988. Mr Gray (Manager Legal Services, UBHT), in WIT 0137, states "In the early days of the PAS system, there were considerable teething problems in respect of the diagnostic coding of cases at the end of treatment episodes. The system did not include the diagnostic coding of operations until the implementation of 'Swift Op' in the early 1990's."

3.15 The possible prognostic factors that are recorded in the PAS data are limited. They include age, diagnosis (or diagnoses) and type of operation planned. The exact clinical condition of the child is not recorded. The diagnosis may be imperfectly coded and recorded.

Statistical Review of the Clinically Coded Records (CCR)

3.16 The Inquiry requested access to the medical records of all children who had undergone cardiac surgery in the period 1984-1995. The UBHT provided these

records to the Inquiry, and Mr Gray gives the details of how this was done in his submission {WIT 0137} referred to above. The PAS and the logs used by the surgeons concerned were each used to identify all such children. The use of the PAS enabled about 80 extra patients' notes to be located. Mr Gray states that approximately 12 sets of notes remain missing for various reasons, from a total of about 1300 "open" and 700 "closed" heart operations estimated to have taken place at Bristol within the period of interest to the Inquiry.

3.17 The available patients' notes have been scanned on to a computer system and made available to the Inquiry team under conditions of strict confidentiality. The Inquiry decided to make a brief summary of each set of notes on a form designed to record the main features of care for the child. This included name, date of birth, gender, hospital record numbers, diagnoses, and operative procedures with dates and surgeons' names.

3.18 The dates of admission and discharge were not extracted from the medical records and so are not available in the CCR. This means that data can be analysed by child, diagnosis or operative procedure, but not by admission.

3.19 A very experienced team of clinical coders carried out the coding of the diagnoses and operations for the CCR. They were used to finding the key information for coding from patients' notes and were also experienced in the clinical field of paediatric cardiac surgery. A description of the coding process has been supplied by the quality assurance manager for the clinical coding project. Any queries that she could not resolve were referred to a senior medical coding consultant in the NHS Information Authority.

3.20 The coded forms were entered on to a computer database (Microsoft Access) by Legal Technologies Ltd, who are responsible for specialised computer technology used by the Inquiry.

3.21 The strengths of this source of data are that the coding was done in a very consistent way, and using very experienced coders. The main limitations relate to the inevitable minor errors in writing on the forms and the possibility of data entry errors being made when entering them on to the computer. The other issue is the quality of the notes themselves, which may be incomplete. In particular the exact dates of procedures are not always known. The amount of information in the original records is vast, but clearly only a very brief summary of each set of notes has been made. Medical information, including death that occurs elsewhere, may not be recorded.

3.22 In most instances there was more than one set of notes relating to a single child, and it was difficult to ensure that all notes which did relate were linked in the computer without error. This was done using names, but there are a number of instances of different children having the same name. All detected errors of this type have been corrected prior to this report being written.

3.23 It would be theoretically possible to have a study that utilised a wider range of prognostic factors than age, diagnosis and operation, using the full paper medical records. However, such a study would need to be set up with careful attention to the various factors, prior to examination of the data.

3.24 The limitations on the CCR data recorded for the purposes of the Inquiry are similar to those on the PAS system in terms of coverage. The consistency of the coding may make these data better than the PAS for analysis, but it is also possible that the missing data will impose severe limitations on the strength of conclusions that may be drawn from the CCR data.

Statistical Review of the Surgeons' Logs (SL)

3.25 These logs originated as hand- or type-written notes recorded by the two surgeons from the BRI and cover the whole period of the Inquiry.

3.26 The witness statements by Messrs Wisheart and Dhasmana describe the reasons behind the creation of these logs *{WIT 0120 0256- 0262 and WIT 0084, 0001-0005}*. They were a primary source of information used by UBHT to identify the relevant clinical records to be supplied to the Inquiry.

3.27 The quality assurance manager for the clinical records coding project has coded the surgeons' logs. They relate only to surgery carried out by Messrs Wisheart and Dhasmana at the BRI. In principle, this means that the surgery recorded was all open-heart surgery, and all such surgery carried out by the two surgeons should be recorded in the logs.

3.28 The logs have the name of the child, and a note of the operation. The following data have been recorded on computer files: age of the child in years, months or days (not date of birth); primary diagnosis, and details including date of the procedure, whether the child is recorded as dying, with date of death and whether a post-mortem was done. Post-operative complications and a note of whether there are extensive comments in the original log are also recorded. The BRI numbers (theoretically allocated to a child and used for all admissions) are also recorded.

3.29 It is important to note that, as with the CCR, the date of admission is not available. This was not recorded on the logs themselves, and so could only be obtained from another source. It is possible to link children by their name, though the spelling of names is not always consistent and the name of a child may change between admissions. Analysis can, in principle, be by child, operation or operative procedure.

3.30 The surgeons themselves used the logs for what is described as a crude form of audit. No formal validation of the data was carried out, but given the state of formal audit in the NHS in 1975 when Mr Wisheart began his log or in 1984

when the period of interest to the Inquiry began, the log was a valuable method for keeping track of operations. Mr Wisheart in his evidence stated that, given the state of the art at the time the log was started, it was an "excellent system, which provided accessible and reliable information, which was not subject to technical failure".

3.31 Some other surgeons carried out a few operations during the relevant time period, notably Mr Pawade, but no log data are available for these operations.

Key points and Conclusion of Overview

3.32 a) Some information on the outcome of care in terms of mortality is available from all three sources.
b) Full assessment of morbidity is absent from virtually all the sources.
c) The CCR and SL cover the whole period of time; the PAS does not.
d) The CCR and PAS cover all operations; the SL only covers those done by Messrs Wisheart and Dhasmana at the BRI itself.
e) The PAS has dates of admission & discharge; the CCR and SL do not.
f) Available data are capable of being used in a broad overview and although each is subject to error in the details, consistency of findings across them would increase confidence in the results.
g) There are likely to be differences in the way the operations are coded, since they rely on different original sources as well as being done by different people.

Data items which all sources have in common

Patient name
Date of operation
BRI number Whether patient died
Surgeon
Date of death
Diagnosis
Age (derived from date of birth for CCR & PAS)
OPCS codes for operative procedures

3.33 Each of the sources has some missing data for several of these items. The quality of the administrative data (names, record numbers and dates) is highest in the PAS, which is the only system to have some form of validation of its records.

3.34 Overall comparisons between death rates are possible. The exact numbers of admissions and deaths and therefore death rates are likely to be different because of the differences in coding and methods of ascertainment. It is possible to try to match individual patients across the sources to carry out crosschecks on the data, but because of the missing and occasionally erroneous data, this process itself has problems. An overall summary by operation group, by age and by calendar year is possible.

4 Results of Activity and Outcomes Analyses

The Patient Administration System (PAS)

Introduction

4.1 The PAS as noted above does not have data prior to 1st January 1988. It is a complex database and only the data relevant to the Inquiry were requested from UBHT.

4.2 The data supplied were on patients who were: -

1 admitted to any United Bristol Hospitals Trust (UBHT) between 1st January 1988 and 31st December 1995 and -
2 aged 16 years or younger on admission and -
3 admitted or transferred to the care of a consultant with a specialty of Cardiothoracic or Paediatric Cardiothoracic Surgery, or Cardiology or Paediatric cardiology and -
4 recorded as receiving procedures under the national specialties "Cardiac Surgery" or "Cardiology".

4.3 The data are divided into three sets; 1- those who received operative procedures under the "Cardiac Surgery" specialty, 2- those who received operative procedures under the "Cardiology" specialty, 3 - those who received care under either specialty but did not have any procedures carried out. The third group has not been included in this report, as they did not have surgery.

4.4 The data are first described under the two categories of specialty, but merging the two sets of data provides the main results. Many children received care under both specialties, and the object is to give a clear picture of the total care received in respect of surgery.

Description of the children who received care

Cardiac Surgery Specialty

Admissions

4.5 PAS data record "episodes" of care. An "episode" in this context is a period of care in hospital under a consultant. A single admission can include several episodes of care, with a new episode arising for example, when a patient is transferred to the care of another doctor. Annex 1 gives an overview of the complex structure of the data. There are 1678 records of episodes. These relate to 1666 admissions/discharges. There are eight admissions with 2 episodes and two admissions with 3 episodes in each. The total number of children is 1420. Of these, 408 do not have a BRI record number and may have had only "closed" heart operations, while 1411 had a BRI record number. Most children (85%) had a single admission, but 15% had two or more admissions.

4.6 The two surgeons JDW & JPD dealt with 93% of the children. Most children were admitted under a single consultant for all their admissions until 1994 and 1995 (in 1995 Mr Pawade became Consultant surgeon).

Deaths

4.7 From the records 244 of the children (17%) are recorded as having died. The date of death was recorded in arrears in batches until 1992, and 12 children are noted as having died with no date of death recorded. Most (128) of the deaths occurred in hospital (55% of those with known dates). A further 7 occurred within 30 days of discharge, but the rest occurred over varying lengths of time up to 10 years after discharge. **This is important for comparison with HES, which in general will not have deaths that are recorded post-discharge from hospital.**

Number and nature of the surgical procedures

4.8 The 1420 children had a total of 3477 operations coded; of the 1678 episodes, all of which had at least one operation coded, there were 1057 with a second, of these 522 had a third and 220 had a fourth operation.

Cardiology Specialty

Admissions

4.9 There are 1985 records of "episodes" involving cardiology. These relate to 1974 admissions/discharges. There are 11 admissions each with 2 episodes. The total number of children is 1426. Most children (75%) had a single admission, but 25% had two or more admissions. The children were admitted in 99% of cases under one of four cardiologists.

Deaths

4.10 Of the 1426 children admitted under the cardiologists, there were 256 who died. In terms of admissions/discharges, there were 359 admissions where a child subsequently died. Forty-five of these were after discharge from hospital. This is of relevance to the use of HES and the comparative analysis of mortality using national sources where recording of death after discharge from hospital is incomplete.

Number and nature of the surgical procedures

4.11 The 1426 children received 2578 procedures in hospital. Very few of the procedures that were done under the care of the cardiologists are coded as being major procedures. There are 6 (out of 2578) procedures classed as being major cardiac surgery which are coding errors. This suggests that the rate of important

coding errors in the PAS is low. Of the 2578 procedures, 2338 were K or L codes in the OPCS classification, most of which correspond to catheterisation or similar procedures. The remaining procedures (240) were not classified as cardiac procedures.

Combining the data from the two sources of the PAS

Admissions

4.12 Many of the children who were admitted under the care of the cardiologists went on to be admitted under the surgeons. The total number of children indicated to have received paediatric cardiac services is in fact 2012; 834 had admissions under both surgeons and cardiologists, 592 only under the cardiologists and 586 only under the surgeons.

4.13 The 2012 children had 3586 admissions in total. Just over half had a single admission; the distribution of admissions is given in table 4.1 and in figure 4.1. The maximum number of admissions per child under cardiology or cardiac surgery was 9.

Number and nature of the surgical procedures

4.14 In the 3586 admissions, there were a total of 6055 operative procedures recorded. The average number of procedures per child was 3, but this ranged from 1 to 18, though there was only one child who received 18 procedures. The distribution of the number of operative procedures received per child is shown in figure 4.2.

4.15 Of the 6055 procedures, 1227 were non-cardiac, and largest proportion of cardiac procedures was catheterisation. The nature of the more complex cardiac procedures is given below.

Analysis of the complex procedures

4.16 As noted at paragraph 4.5 above, the analysis cannot be done using a child as the basis for analysis in the nationally available data. The basis has to be an admission. Hence in the analysis given below, the results are derived from the 3586 admissions. For each of these admissions, the most complex operative procedure was selected according to a ranking procedure {see sections 2.2.2 to 2.2.4 of the HES report}. The admissions were thus divided among 13 procedure groups ranked for complexity. In addition a separate exercise was done to divide the operations into open- or closed heart procedures where this was clear from the coding. Further details of this process are given in the HES report in sections 2.2.5 to 2.2.7, and in section 2.4.5.

4.17 The pattern of numbers of children, admissions, operations and operative procedures from the data in the PAS is shown in figure 4.3. Some children had more than one operative procedure in one of the 13 groups in a single admission.

4.18 For the purposes of analysis children who are aged 16 and over at the time of their operation are not included; this leaves a total of 1285 admissions for 1147 children. The number in each group is given in table 4.2, together with the number who died and their mortality rate. These 1285 admissions are used for comparison between the other local and national sources of data relating to the 13 groups. The tables contain operations only from these groups.

4.19 For the purposes of analysis, the data are divided into four epochs {see HES report}. The PAS data are only available for three of the epochs, and the number of admissions, deaths and death rate by epoch are given in table 4.3. The death rates overall are much lower in the third epoch, but the number of admissions is less than 30% of the numbers in the other two epochs. The results for age groups are in Table 4.4. The overall death rate for operations in the first year of life is

more than twice that at later ages.

4.20 The diagnosis for each admission is not shown here, and diagnosis will be discussed briefly in the next section (CCR).

Deaths

4.21 Of the 2012 children, 331 are recorded in the PAS database as having died; 187 of them died within 30 days of an operation. Sixteen children were recorded as having died, but with no date of death. Of the 187 who died within 30 days of an operation, 14 died after discharge from hospital. A further 117 died following discharge from hospital more than 30 days after their last operation. Eleven died in hospital more than 30 days after an operation.

4.22 We do not have, in the available data, any certain information on the status of those who were alive on discharge from hospital. At 2.1 and 3.8 above, it is noted that the Bristol PAS does have data on deaths post-discharge from hospital which is relatively unusual, but the completeness of this recording is unknown. It is possible to assume that all those who have died have been notified to the hospital, but it has not been possible to verify this. A survival curve that must be treated with great caution has been drawn as figure 4.4. This takes the date of the last operation recorded for a child as the first date, and the date of death or 1st January 1999 as the last date. (There are three children, whose operations are recorded as being within the timescale of the Inquiry, who died in the first three months of 1999). The 16 children whose date of death is unknown are assumed to have been alive at the date of discharge. *{Technical note: survival times have had 1 added to them; 62 children died on the date of the operation and zero failure times would be excluded}.*

4.23 Figure 4.4 shows that, overall, 90% of the children were still alive at 30 days. The survival curve does continue downwards beyond this point, but at a low rate.

Clinically Coded Medical Records (CCR)

Introduction

4.24 The summary data from each child's medical records have been summarised from the computer database created for the purpose of the Inquiry. The terms of reference include children seen between 1984 and 1995. A number of records supplied to the Inquiry were found to be outside the terms of reference. This report relates to the data from patients whose records were: -

1 supplied to the Inquiry team, though they did not necessarily have a surgical procedure coded from the medical records and -
2 on the database created by Legal Technologies Limited and -
3 within the terms of the inquiry (a total of 164 records have comments made by those doing the coding to the effect that they were out of the timescale of the Inquiry)
4 having their at least one recorded operation within the timescale (2 records found to be out after the preliminary analysis)

Description of the children who received care

4.25 There were 2050 children in the CCR database, but there were 166 immediate exclusions. There were a few (9) records that the coding team was unable to code, so that the data from these were limited. The number of children is then reduced to 1875, of whom 1361 have a date of operation after 1st January 1988 (allowing comparison with PAS data which started at that time). A number of errors of detail in the records have caused procedures for some of the 1875 children to be excluded from analysis. The process of finding errors in these data has continued,

and the results given are based on the corrected data as at September 1999.

4.26 The data for children, operations and operative procedures are displayed in similar ways to those shown for the PAS, in figure 4.5. As noted at section 3.18 above, the admission dates were not extracted when the medical records were coded for the CCR. The number of operations per admission in the PAS was only 1.05; this means that any error resulting from use of operation as the unit of analysis, instead of admission, will be small. Tables 4.5 to 4.7 are similar to those shown for the PAS as tables 4.2 to 4.4. These show the numbers of operations, deaths within 30 days of operation and death rates by the 13 groups (Table 4.5), for the epochs (Table 4.6) and for age groups (Table 4.7).

Diagnosis

4.27 Diagnosis is available on all three sets of data, but the main comparative analyses do not include diagnosis at this stage. (Diagnosis is not recorded as such in the UK Cardiac Surgical Register - UKCSR). Analyses have been done using the ICD 9 coding system. This has classified diagnosis by child as opposed to admission. For most there is only a single code, but 157 children have two diagnostic codes. There are a large number of individual codes or combinations, many of which occur only once (101) or twice (52). Over 80% of the children have one of the more common diagnoses that occur at least 20 times.

4.28 The primary diagnosis codes that occur at least 20 times in the CCR are given in Table 4.8, with the percentage who died. The overall death rate in those whose vital status was known was 19.2%. The level of detail offered by the ICD codes when using all available digits for the classification is considerable. It is clear from Table 4.8 that the death rate shows considerable variation according to diagnosis. If these data were available nationally and were of comparable quality in different hospitals, then they might be used to help in defining pre-operative risk. However, it seems that from surgeons' opinions {see transcripts for

September 14th & 15th 1999}, even this level of detail may not reflect the true pre-operative risk.

4.29 All the surgeons, including junior doctors, are linked in the records to the operative procedures that were carried out. This covers 420 different individuals. 6676 procedures were carried out on the children, and about 50% of them had several surgeons coded as involved in at least one stage of the procedure. Most children were seen by at least one of the two main consultant surgeons.

Surgeons' Logs

Introduction

4.30 The Surgeons' log books were a manual record as described at sections 3.25 to 3.31 above. They were coded using the same methodology as that used for the CCR, and stored on an Access database. The surgeons' logs do not have dates of admission or other administrative details on them. Dates of birth are not recorded, though age (in years or months or weeks or days) is recorded.

Description of the children who received care

4.31 There are 1244 children with records in the surgeons' logs. These children had a total of 1318 operations with a total of 2246 procedures coded. Most (2056) of these procedures were coded as cardiac. Figure 4.6 shows the pattern of the numbers of children, operations and operative procedures. The ratio of coded procedures to children is lower than for the other sources. It is also clear that most operations are classified as "open" and are grouped in the 13 groups.

4.32 Tables 4.9 to 4.11 are similar to those shown for the other sources. As for the other sources, they are based only on those operations that are in the 13 groups. There are few operations in groups 12 and 13, which are closed operations. The

death rates shown in Table 4.9 show that the highest death rates are for switch operations ("Other TGAs") and for truncus arteriosus repair.

5 Results of Comparative Analyses of Activity and Outcomes

5.1 The period that the data sets cover is not the same, but for the years 1988 to 1995, there are some differences in overall numbers. There are a total of 1361 children in the CCR database, but 2012 in the PAS. This suggests that many (651) medical records have not been found and passed to the inquiry team. However, the main difference is in the number of those recorded in the PAS who had minor procedures, including those who, although admitted under the care of cardiologists or cardiac surgeons, did not have a cardiac procedure at all.

5.2 A clearer picture is shown by making comparisons using the operations classified by the 13 groups. Table 5.1 shows the data analysed by epoch and by open/closed operation for the three sources. It should be noted that the death rate is similar in all three sources for most of the groups. There is a notable difference relating to the two types of TGA: the SL database has a lower rate for "Interatrial TGA" but a higher rate for "Other TGAs". "Fontan type" operations have not been coded as frequently in the SL as in the other two sources, and the CCR has much lower numbers than the PAS.

5.3 As expected, the numbers of closed operations are very much lower in the SL than in the other two, and it is possible that even the 23 "Closed shunts" are mainly a result of coding errors.

5.4 It should be remembered that the PAS does not cover the full period of interest to the Inquiry, so that its numbers might be expected to be rather lower. Table 5.2 shows this clearly, where in fact it is seen that in any comparable epoch the PAS has slightly more records of admissions than the CCR has procedures, and notably

more than the SL.

5.5 Detailed data for each epoch, age group and type of operation are shown graphically from Figure 5.1 onwards. Figure 5.1 shows the values of the number of admissions (PAS) or operations (CCR & SL) for each source of data plotted against the others. It is clear from figure 5.1, which has the three comparisons PAS-CCR, PAS-SL and SL-CCR, that the overall numbers are similar, but there is not perfect agreement. If there were perfect agreement, all points would lie exactly on the straight line (of identity). In the first graph of Figure 5.1, there is no strong tendency for points to lie above or below the line. There are a few more points above the line suggesting that the PAS has a larger number of admissions recorded in any comparable group. The scatter around the line suggests that the overall numbers of equivalent operations are similar in the PAS and CCR, but there are disagreements in the exact group to which an operation or admission is allocated. The same is not true of the Surgeons' logs (SL), where there is a systematic tendency for the numbers to be rather lower. This point is reinforced by examining Table 5.2, which shows that, in each epoch where a comparison is possible, the numbers of admissions or operations are relatively similar for the PAS and CCR but notably lower for the SL. There are slightly higher totals in the PAS than in the CCR in each epoch.

5.6 A similar pattern exists for the numbers of deaths, though from the graphs in Figure 5.2 they seem to be more variable. This is mainly because the absolute numbers are smaller, so relative discrepancies seem larger. The scale is from zero to ten rather than to 100, as in the graphs for the number of admissions. The overall impression is that the numbers are similar in the PAS and CCR but smaller in the SL. There is still some disagreement in individual categories, but this is due to misclassification of the diagnostic groups. This is confirmed by the entries for deaths in Table 5.1.

5.7 When we examine death rates related to the 13 procedure groups then the variation appears (Figure 5.3) to be much greater. This is because of the small numbers in a particular epoch/age/procedure type group. A mortality rate can only be 100% or 0% when there is only one procedure. Very small discrepancies in the numbers can lead to large apparent variation.

5.8 The systematic difference between the SL and the other two sources requires explanation. The PAS and CCR count all operative procedures done by all surgeons, whether open or closed, whether done at the BRI or at the BRHSC. The SL relates only to open heart operations (though some procedures may be done which could be done as closed heart operations), carried out at the BRI by Messrs Dhasmana and Wisheart. The numbers of operations done by Mr Wisheart in 1995, particularly after 1st April, was small.

5.9 The method of classification by 13 procedure groups shows similarities between different sources of data. The actual numbers are not perfectly reproducible across the different sources, because of

1 differences in coding
2 differences in methods of obtaining data, especially deaths
3 differences in definitions (operations, admissions, procedures)

5.10 These differences do not invalidate the data, but make it clear that single findings, using a single source, should be treated with caution. Findings that apply across several different sources will be more reliable.

5.11 The operative procedures were also classified simply into open and closed operations. A similar set of graphs to those in figures 5.1, 5.2 & 5.3 (Figures 5.4, 5.5 & 5.6) are shown for the data divided simply into "open" and "closed" operations. They are based on larger numbers of procedures and deaths contributing to each point, and there is less room for misclassification. The relationships between the three different sources are seen to be stronger.

5.12 The three sources show reasonable agreement for open operations, but the SL has, as expected, very few closed operations. This confirms that the method of classification is reasonable and that the coding of the SL is consistent. There is still a tendency for the PAS to record more admissions overall, and for the CCR to perhaps have more deaths recorded than the other sources. The PAS and CCR show reasonable agreement for closed operations. It is important to note that most of the tables have been restricted to those operations that are classified into the 13 groups. This excludes a number of operations, but the death rate in these operations is very much lower. This allows for comparison with the national sources of data, but its limitations must be borne in mind.

Individual record checking - Comparing CCR, PAS & medical records

5.13 A great deal of crosschecking on the individual records among the three sources has been done. This is not simple since children may change their names, they may be re-admitted and given a different hospital record number, their dates of birth may be recorded incorrectly. The checking for this exercise was confined to objective information such as dates and vital status. In this process, very few discrepancies were found in the PAS when compared with the medical records. One death noted in the medical records was not recorded in PAS. A few discrepancies caused by coding or data entry errors have been found by comparing the CCR and PAS with the medical records. Similarly, comparing the CCR and SL, discrepancies have been found attributable to errors in data entry, coding or the SL itself.

5.14 The coding of operative procedures was not checked in this way. The volume of work required would be very large indeed. Some checking will be done as part of the clinical notes review exercise done on the sample of children's notes reviewed by the clinical expert teams. A separate report on this exercise is being prepared.

5.15 Table 5.4 presents overall results split by the two surgeons, based on their logs. The overall and individual death rates are rather similar except where the numbers are small. For truncus operations, there is a higher rate for Mr Wisheart, but even this difference is based on numbers that are too small to eliminate an effect of chance.

6 Summary and Conclusions

6.1 The data from the PAS has generally been found to be of high quality. They are not recorded according to child, but with statistical or other software it is possible to link episodes of care to form a picture of what happens to each patient. The individual diagnostic codes may have limitations but for an overall summary, including that on mortality, the Bristol PAS has potential for use in audit.

6.2 It was anticipated that since the PAS was an administrative system the overall quality of its medical and outcome information would be very limited. This has not proved to be the case.

6.3 The exercise of coding the medical records was a considerable task, and although the individual coding has been of high quality, there have been many minor problems with the data. It would not be sensible to attempt to repeat this in a routine way, and the PAS seems to provide an adequate method for an overview of the amount of care and the mortality. The coding and entry on to a computer of the SL has also required a major resource. Doing this retrospectively without contemporaneous validation is much less valuable than having a computer system used by clinicians at the time. The problem is that there needs to be agreement on grouping the operative procedures and diagnostic categories. From a clinical perspective, it is important to realise that each child is unique and not simply to be "pigeon-holed". However, in order for comparisons to be made, either over time or between surgeons in a unit, or between units, some categorisation has to be

done. Inevitable imperfection in the categories will mean that comparisons are less sensitive than if knowledge were to be perfect, but comparison is the only way to achieve progress.

6.4 Morbidity is very much more difficult to categorise, and any attempt to provide an overall assessment is likely to be difficult. Morbidity in paediatric cardiac surgery is a quite different issue to that in paediatrics in general or to care of the elderly.

6.5 It has been useful to obtain the PAS data for cross-checking.

6.6 The great majority of the children who received care did not die.

6.7 The use of the CCR has enabled a sample of individual clinical medical records to be taken in an objective way. This is of great importance, both in terms of being representative of all the cases, and in allowing scrutiny to take place without two thousand individual records being evaluated in detail.

6.8 There is no evidence to suggest that there was any marked difference in the mortality rates of the two surgeons for similar operations.

Acknowledgements

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The help of the Secretariat to the Inquiry, particularly Ruth Chadwick, is gratefully acknowledged. Many of the team contributed to the work of checking the data.

Tables for PAS

Table 4.1

PAS - The number of admissions per child for 2012 children with 3586 admissions

Number of admissions	Frequency	Percent	Cumulative %
1	1079	54	54
2	590	29	83
3	188	9	92
4	75	4	96
5	49	2	98
6	14	1	99
7	6	0.3	99
8	7	0.3	100
9	4	0.2	100
Total	2012	100	

Table 4.2

PAS – Admissions, deaths within 30 days of operation and death rates in 13 groups, 1285 admissions

Group	Admissions	Deaths	Death rate %
Tetralogy of Fallot	110	15	14
Interatrial TGA	69	7	10
Other TGAs	42	16	38
TAPVD	34	12	35
AVSD	88	20	23
Closure of ASD	168	7	4
Closure of VSD	198	12	6
Truncus Arteriosus	17	8	47
Fontan type	74	9	12
Aortic, pulmonary valve procedures	105	7	7
Mitral valve procedures	44	7	16
Closed shunts	146	13	9
Coarctation procedures	190	6	3
Total	1285	139	11

Table 4.3

PAS - Admissions, deaths within 30 days of operation and death rates by year of operation, those in the 13 groups only.

Epoch	Admissions	Deaths	Death rate %
Jan88-Dec90	476	60	13
Jan91-Mar95	677	76	11
Apr95-Dec95	132	3	2
Total	1285	139	11

Table 4.4

PAS - Admissions, deaths within 30 days of operation and death rates by age at time of operation, those in the 13 groups only

Age group	Admissions	Deaths	Death rate %
0-90 days	220	39	18
91-365 days	297	50	17
1-15 years	768	50	7
Total	1285	139	11

Tables For CCR

Table 4.5

CCR – Operations, deaths within 30 days of operation and death rates in 13 groups for 1662 operations

Group	Operations	Deaths	Death rate %
Tetralogy of Fallot	162	22	14
Interatrial TGA	78	4	5
Other TGAs	23	7	30
TAPVD	38	12	32
AVSD	73	22	30
Closure of ASD	312	28	9
Closure of VSD	263	20	8
Truncus Arteriosus	18	11	61
Fontan type	33	9	27
Aortic, pulmonary valve procedures	131	10	8
Mitral valve procedures	58	12	21
Closed shunts	225	32	14
Coarctation procedures	248	12	5
Total	1662	201	12

Table 4.6

CCR – Operations, deaths within 30 days of operation and death rates by year of operation, those in the 13 groups only

Epoch	Operations	Deaths	Death rate %
Jan84-Dec87	486	56	12
Jan88-Dec90	461	69	15
Jan91-Mar95	615	73	12
Apr95-Dec95	100	3	3
Total	1662	201	12

Table 4.7

CCR – Operations, deaths within 30 days of operation and death rates by age at time of operation, those in the 13 groups only

Age group	Operations	Deaths	Death rate %
0-90 days	283	56	20
91-365 days	362	61	17
1-15 years	1017	84	8
Total	1662	201	12

Table 4.8

CCR- Table of children with diagnostic codes.
Only those codes that occurred at least twenty times as single codes are listed.
The percentage dying is the percentage recorded as dying within the medical notes, not just within 30 days of an operation.

Diagnosis	Frequency	% who died
Common Truncus	27	52
Transposition of Great Vessels	191	33
Tetralogy of Fallot	175	17
Common Ventricle	29	34
Ventricular Septal Defect	211	11
Ostium Secundum Type Atrial Septal Defect	182	3
Endocardial Cushion Defects	101	35
Anomalies of Pulmonary Valve	35	23
Tricuspid Atresia And Stenosis	27	30
Congenital Stenosis of Aortic Valve	27	22
Other Congenital Anomalies of Heart	34	18
Patent Ductus Arteriosus	191	4
Coarctation of Aorta	202	13
Anomalies of Pulmonary Artery	49	35
Stenosis of Vena Cava	56	45

Table 4.9

SL – Operations, deaths within 30 days of operation and death rates in 13 groups for 1132 operations, those in the 13 groups only

Group	Operations	Deaths	Death rate %
Tetralogy of Fallot	173	25	14
Interatrial TGA	101	1	1
Other TGAs	27	11	41
TAPVD	52	14	27
AVSD	98	24	24
Closure of ASD	251	25	10
Closure of VSD	244	17	7
Truncus Arteriosus	21	10	48
Fontan type	6	1	17
Aortic, pulmonary valve procedures	113	5	4
Mitral valve procedures	17	7	41
Closed shunts	23	10	43
Coarctation procedures	6	0	0
Total	1132	150	13

Table 4.10

SL – Operations, deaths within 30 days of operation and death rates by year of operation

Epoch	Operations	Deaths	Death rate %
Jan84-Dec87	323	40	12
Jan88-Dec90	326	48	15
Jan91-Mar95	458	61	13
Apr95-Dec95	25	1	4
Total	1132	150	13

Table 4.11

SL – Operations, deaths within 30 days of operation and death rates by age at time of operation

Age group	Operations	Deaths	Death rate %
0-90 days	84	37	44
91-365 days	346	60	17
1-15 years	702	53	8
Total	1132	150	13

Table 5.1

Admissions/operations, deaths and death rates for the three sources, split by the 13 operation groups

Group	PAS		CCR		SL	
	Deaths/ Admissions	Death rate %	Deaths/ Operations	Death rate %	Deaths/ Operations	Death rate %
Tetralogy of Fallot	15/110	14	22/162	14	25/173	14
Interatrial TGA	7/ 69	10	4/ 78	5	1/101	1
Other TGAs	16/ 42	38	7/ 23	30	11/ 27	41
TAPVD	12/ 34	35	12/ 38	32	14/ 52	27
AVSD	20/ 88	23	22/ 73	30	24/ 98	24
Closure of ASD	7/168	4	28/312	9	25/251	10
Closure of VSD	12/198	6	20/263	8	17/244	7
Truncus Arteriosus	8/ 17	47	11/ 18	61	10/ 21	48
Fontan type	9/ 74	12	9/ 33	27	1/ 6	17
Aortic, pulmonary valve procedures	7/105	7	10/131	8	5/113	4
Mitral valve procedures	7/ 44	16	12/ 58	21	7/ 17	41
Closed shunts	13/146	9	32/225	14	10/ 23	43
Coarctation procedures	6/190	3	12/248	5	0/ 6	0
Total	139/1285	11	201/1662	12	150/1132	13

Table 5.2

Admissions/operations, deaths and death rates for the three sources, by epoch for the 13 groups combined

Epoch	PAS		CCR		SL	
	Deaths/ Admissions	Death rate %	Deaths/ Operations	Death rate %	Deaths/ Operations	Death rate %
Jan84-Dec87	-	-	56/486	12	40/323	12
Jan88-Dec90	60/ 476	13	69/461	15	48/326	15
Jan91-Mar95	76/ 677	11	73/615	12	61/458	13
Apr95-Dec95	3/ 132	2	3/100	3	1/ 25	4
Total	139/1285	11	201/1662	12	150/1132	13

Table 5.3

Admissions/operations, deaths and death rates for the three sources, by age group for the 13 groups combined

Age group	PAS		CCR		SL	
	Deaths/ Admissions	Death rate %	Deaths/ Operations	Death rate %	Deaths/ Operations	Death rate %
0-90 days	39/220	18	56/ 283	20	37/ 84	44
91-365 days	50/297	17	61/ 362	17	60/ 346	17
1-15 years	50/768	7	84/1017	8	53/ 702	8
Total	139/1285	11	201/1662	12	150/1132	13

Table 5.4

Surgeons' Logs derived operations, deaths and death rates for the two principal surgeons, by the 13 groups 1984-1995.

Group	Dhasmana		Wisheart	
	Deaths/ Operations	Death rate %	Deaths/ Operations	Death rate %
Tetralogy of Fallot	7/ 61	11	18/112	16
Interatrial TGA	1/ 45	2	0/ 56	0
Other TGAs	9/ 22	41	2/ 5	40
TAPVD	5/ 23	22	9/ 29	31
AVSD	11/ 56	20	13/ 42	31
Closure of ASD	19/134	14	6/117	5
Closure of VSD	6/116	5	11/128	9
Truncus Arteriosus	2/ 8	25	8/ 13	62
Fontan type	0/ 2	0	1/ 4	25
Aortic, pulmonary valve procedures	3/ 44	7	2/ 69	3
Mitral valve procedures	2/ 6	33	5/ 11	45
Closed shunts	4/ 6	67	6/ 17	35
Coarctation procedures	0/ 3	0	0/ 3	0
Total	69/526	13	81/606	13

Figure 4.1

Distribution of the number of admissions per child in the PAS

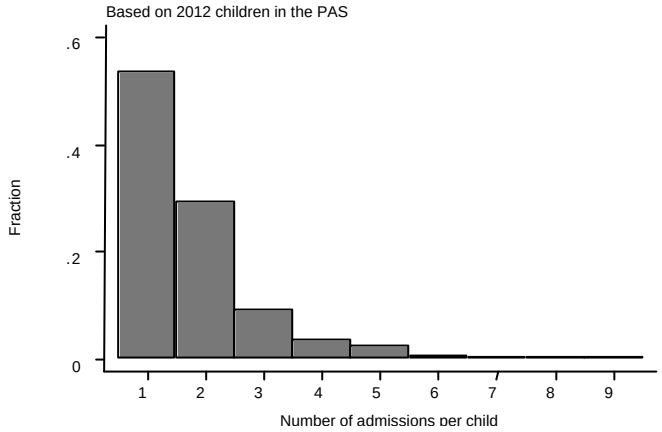


Figure 4.2

Distribution of the number of operative procedures per child in the PAS

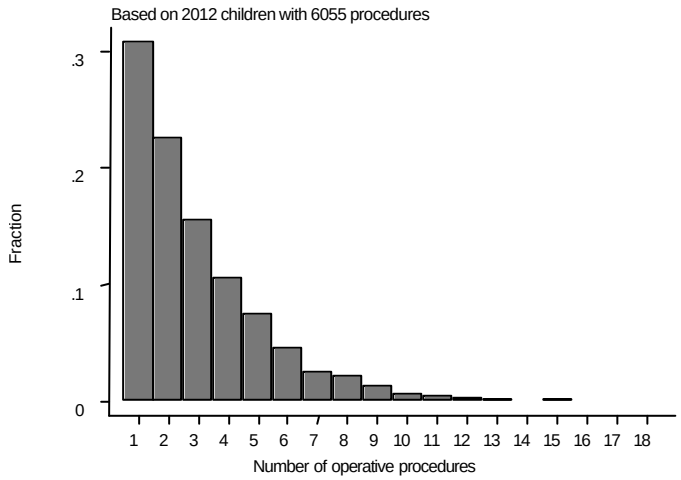


Figure 4.3

Total numbers of children, admissions, operations and operative procedures in the PAS
Admissions divided into open, closed or not classified.
Procedures divided into non-cardiac, cardiac operations in the 13 groups, and cardiac procedures not in the 13 groups

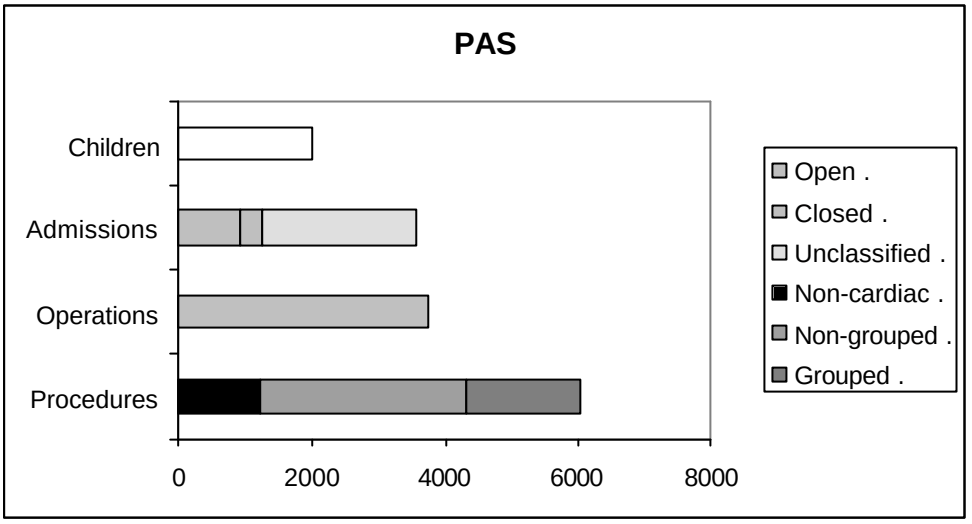
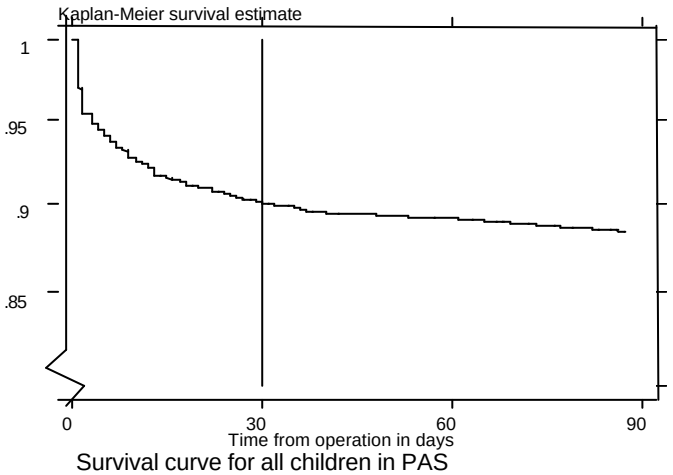


Figure 4.4

Survival curve for all children derived from data in the PAS. Date of first operation as entry point.



Survival curve for all children in PAS

Figure 4.5

Total children, operations and operative procedures in the Coded Clinical Records
Operations divided into open, closed or not classified.
Procedures divided into non-cardiac, cardiac operations in the 13 groups, and cardiac procedures not in the 13 groups

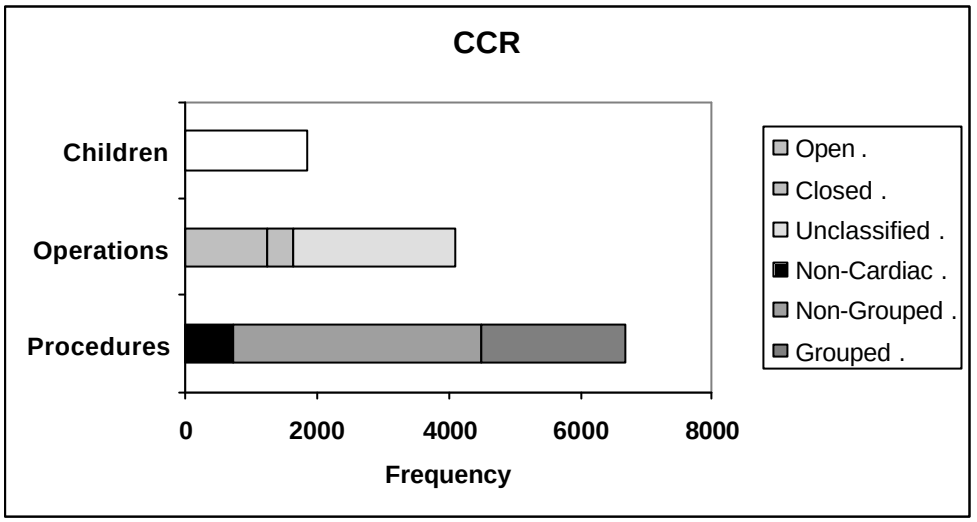
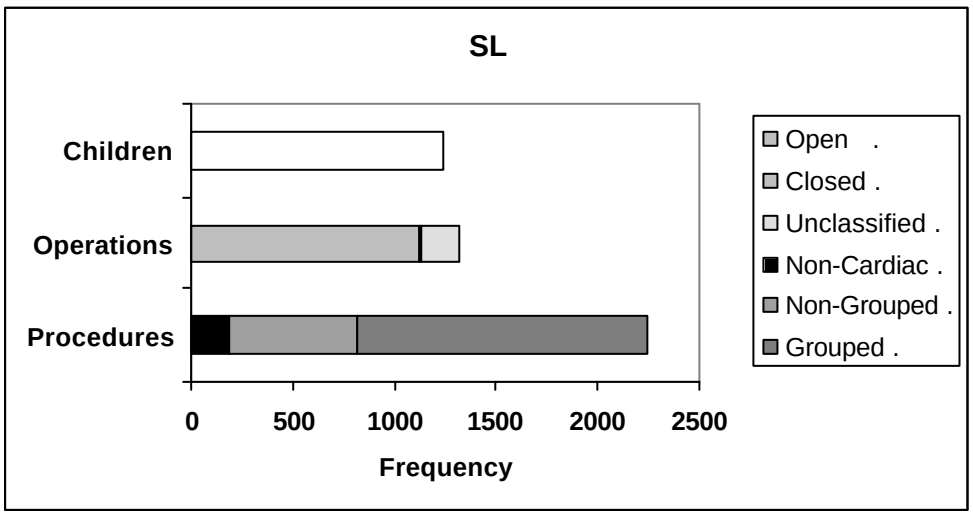


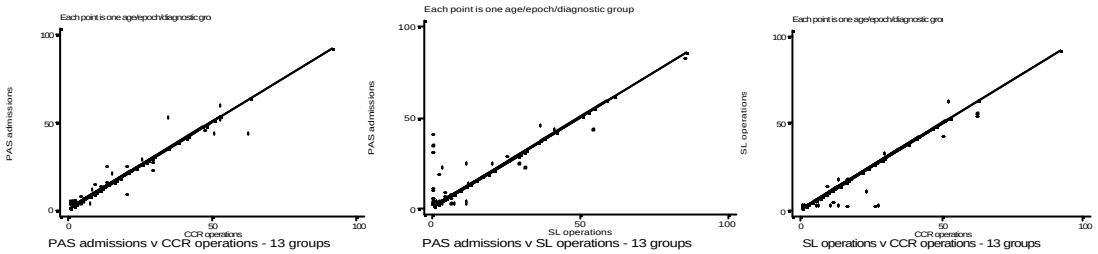
Figure 4.6

Total numbers of children, operations and operative procedures in the Surgeons' Logs
Operations divided into open, closed or not classified.
Procedures divided into non-cardiac, cardiac operations in the 13 groups, and cardiac procedures not in the 13 groups



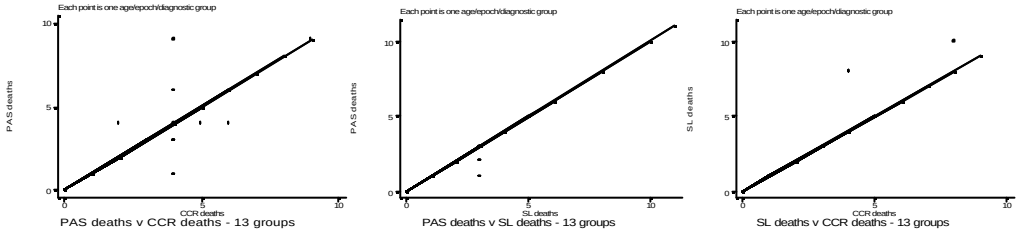
Figures 5.1

Numbers of admissions (PAS), operations (CCR and SL) by epoch, age group and 13 operative procedure groups.



Figures 5.2

Numbers of deaths within 30 days of operation for PAS, CCR and SL by epoch, age group and 13 operative procedure groups.



Figures 5.3

Death rates for PAS, CCR and SL by epoch, age group and 13 operative procedure groups.

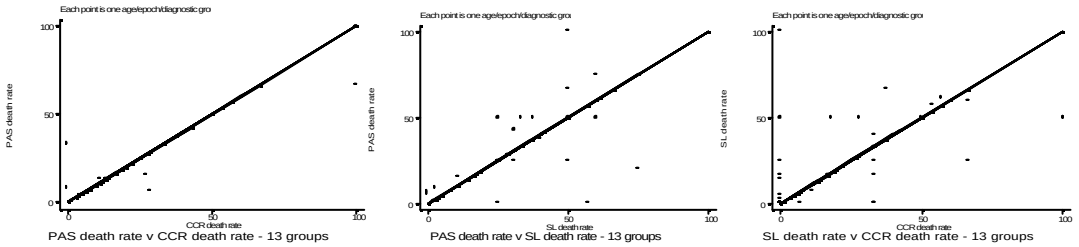


Figure 5.4

Numbers of admissions (PAS), operations (CCR and SL) by epoch, age group and open or closed procedure

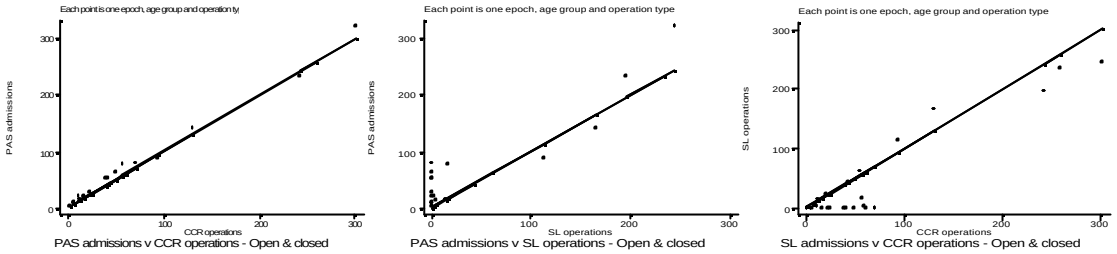


Figure 5.5

Numbers of deaths within 30 days of operation for PAS, CCR and SL by epoch, age group and open or closed procedure

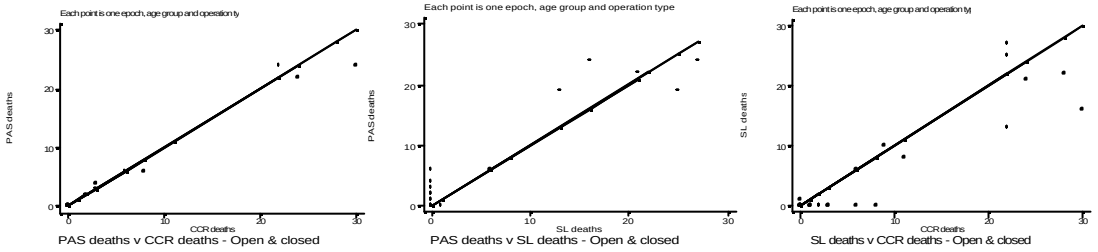
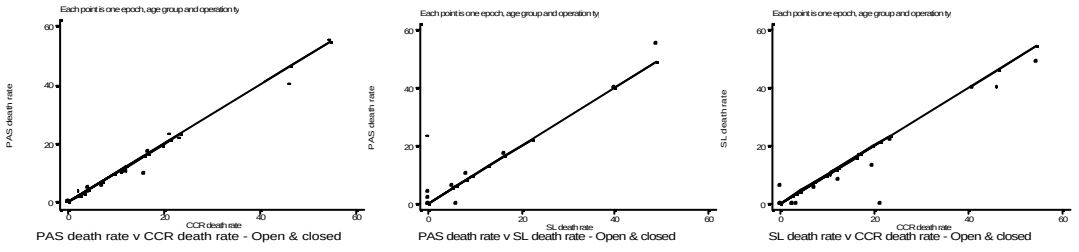


Figure 5.6

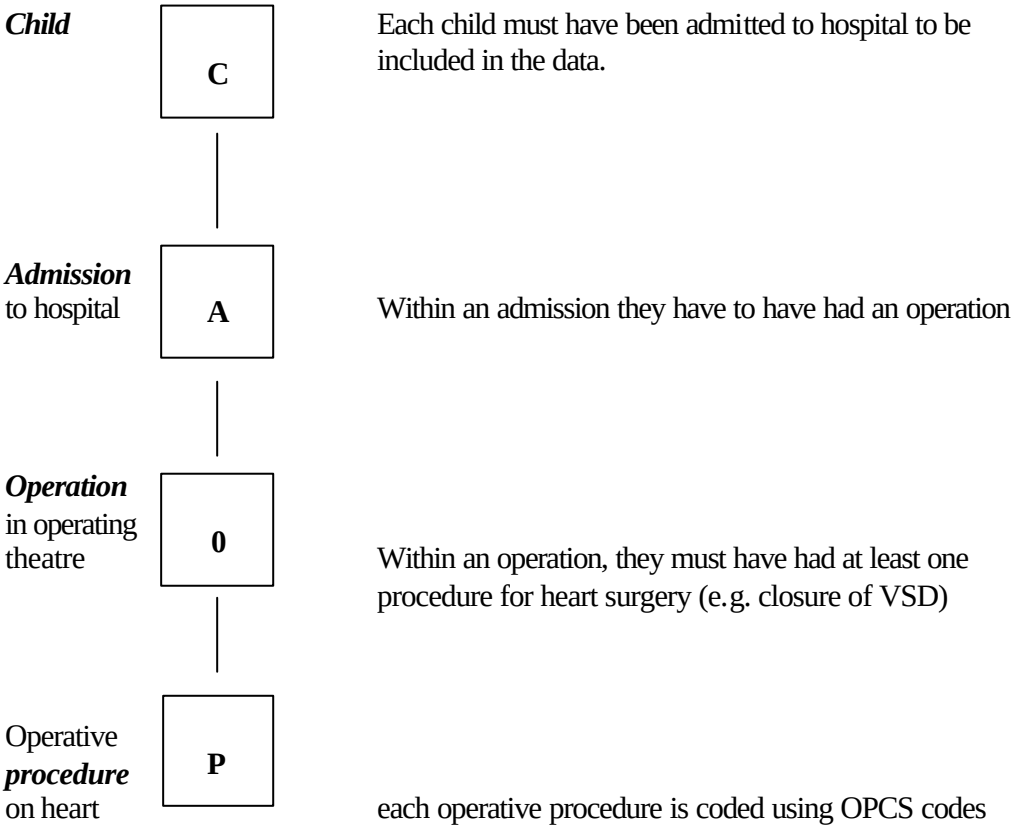
Death rates for PAS, CCR and SL by epoch, age group and open or closed procedure



Annex 1

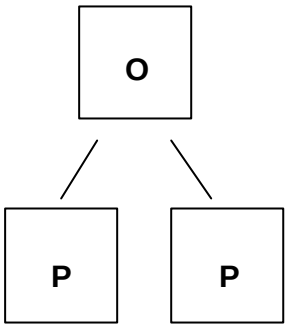
Outline description of data used in analysing mortality following heart surgery in children

The data are collected from various different sources but they all relate to children who have had heart surgery. Inclusion in the data depends on the patient being admitted as an in-patient (i.e. having an overnight stay).

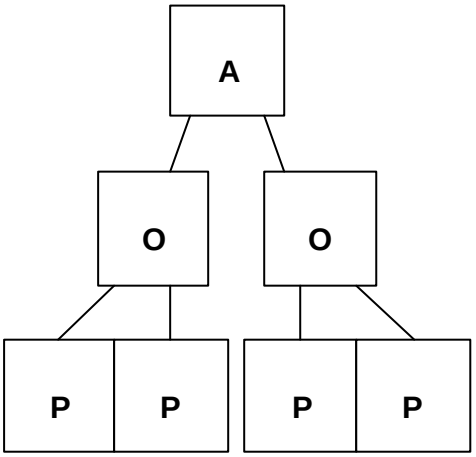


In the simplest case a child has one of each of these; one admission, one operation and one operative procedure, as illustrated above.

However, a child may have more than one procedure in an operation, for example closure of VSD together with an aortic valve procedure:

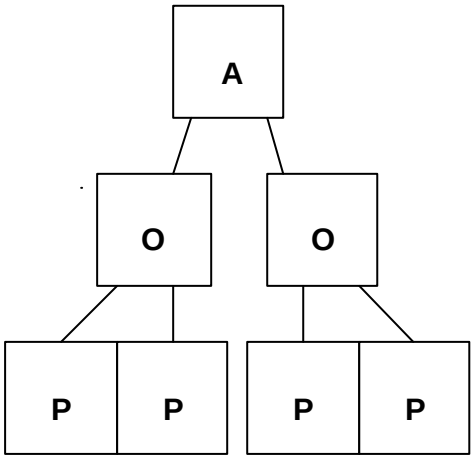


During a single admission to hospital (sometimes called a spell), they may have had more than one operation; each operation may have included more than one procedure:

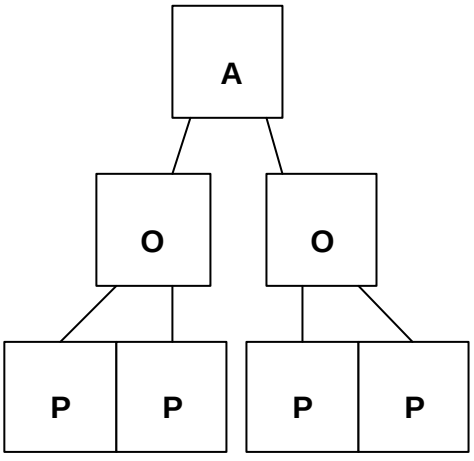


They may also have one admission to hospital, be discharged following their operation, then be re-admitted to hospital for a further operation:

Admission 1



Admission 2



In order to analyse the data and provide a summary of the surgery a decision has to be made as to how to present the data.

For the locally available data it is possible to present results at any level; child, admission, operation or operative procedure.

For the nationally available data it is not possible to analyse by child because individual children are not identified, mainly because of the need to maintain confidentiality. Thus it is not possible to identify cases where the same child is treated on more than one occasion, or in more than one centre.

The team of statistical and epidemiological advisors has decided to base the analysis on admissions. This minimises the multiple counting which would occur if operation, or even worse, operative procedure were to be the basis of analysis.

It has some multiple counting of children in that those who have two admissions may appear in the results more than once.

A single admission may include more than one operation and perhaps several operative procedures. For each admission, the most major operative procedure is noted. For most of the sets of data that are analysed, this procedure has been coded using the OPCS codes that are used nationally. The procedures are put into 13 groups that are regarded as relatively similar by expert cardiac surgeon opinion and also mirror, to a considerable degree, the groups used in the UK Cardiac Surgical Register.

The operative procedures are also classified as “open” or “closed”, again based on expert opinion, where the OPCS code permits such an unequivocal classification. This process is imperfect, and a considerable number of coded procedures have not been put into one of the 13 groups or into one of the two classes –open or closed.

The process of grouping and classification has been carried out in as consistent a way as possible for each of the data sources analysed, and the synthesis of the different data sources is therefore possible. The limitations of the method as applied to each individual data source are described separately.