Analysis of Hospital Episode Statistics for the Bristol Royal Infirmary Inquiry

27/10/99

Division Primary Care & Population Health Sciences
Imperial College School of Medicine, St. Mary's Campus

Dr Paul Aylin
Clinical senior lecturer in Epidemiology and Public Health

Bernadette Alves
Researcher

Adrian Cook
Researcher

Dr James Bennett
Statistician

Alex Bottle
Researcher

Dr Nicky Best
Lecturer in Statistics

Bruna Catena
Researcher

Professor Paul Elliott
Professor of Epidemiology

Division Primary Care & Population Health Sciences
Imperial College School of Medicine, St. Mary's Campus
Norfolk Place
London W2
0171 594 3334
p.aylin@ic.ac.uk

Executive Summary

This report has been commissioned to provide analysis of Hospital Episode Statistics (HES) for the Bristol Royal Infirmary (BRI) Inquiry. It is in 5 sections. The first section is a review of the quality of hospital activity data over the period of the Inquiry (1984-95). We conclude that data covering the years prior to 1991 should be discounted because they are either based on too small a sample, of poor quality or unavailable. For recent years however (1991/92 onwards), HES data provide a source of potentially useful information.

The remaining four sections report the results of our analysis of HES data relating to paediatric cardiac surgery at United Bristol Healthcare NHS Trust (UBHT) - comprising the Bristol Royal Infirmary and the Bristol Royal Hospital for Sick Children - and elsewhere in England between 1st April 1991 and 31st December 1995:

- Outcomes of paediatric cardiac surgery at UBHT in comparison with the combined experience of paediatric cardiac centres in the rest of England
- Comparison of outcomes for individual centres carrying out paediatric cardiac surgery in England
- Activity and referrals
- Co-morbidity and casemix

The results of these analyses are summarised as follows:

Comparison of outcomes

Two broad classes (open or closed) and 13 groupings of procedures (11 open and 2 closed) were developed in consultation with expert clinicians. An open operation is one in which the heart needs to be stopped and the patient put on a heart lung machine. Outcomes were calculated for each group and class for three age groups (under 90 days, 90 days to under 1 year, 1 to 15 years).

For all procedures groups and classes in each age group we calculated mortality rates for UBHT and all other centres combined and the ratio between them. We allowed for chance variation by calculating 95% confidence intervals (95%CI) around our estimates of mortality. If the 95% confidence intervals do not overlap, we can be confident that the difference in mortality is unlikely to be due to chance. However, this analysis does not take into account possible additional variability in mortality rates between individual cardiac centres. We therefore refined the analysis to include an estimate of between centre variation. The difference in performance between UBHT and a typical centre was quantified by predicting the number of deaths expected in UBHT if the typical mortality rate applied there, and comparing this to the observed number of deaths. The resulting difference between the observed and the expected numbers gave us an estimate of the excess number of deaths in UBHT, together with a 95% interval to allow for chance variation.

The main analysis related to the period 1st April 1991 and 31st March 1995:

Children aged under 90 days

- Open procedures in UBHT had a mortality (63%, 95%CI 44-80%) four times higher (4.0) than elsewhere in England (16%, 95%CI 14-18%). The number of excess deaths from open procedures was estimated to be 13.9 (95% interval 8-18) among a total of 19 deaths, and in this age group mortality in UHBT for open procedures ranked the worst among all centres with very high probability.

- Among the 11 specific open procedures, switch (other operations for Transposition of Great Vessels, TGA) procedures had mortality (90%, 95%CI 55-100%) which was nine-times higher (8.9) than elsewhere (10%, 95%CI 8-13%), with an estimated 7.8 (95% interval 5-9) excess deaths among a total of 10 deaths. In this age range, numbers in many other procedure groups were too small to make robust comparisons and no other groups had a significantly high mortality.

- Closed procedures in this age group had the same mortality (5%, 95%CI 2-12%) as elsewhere (5%, 95%CI 4-6%).

Children aged 90 days to under 1 year

- Open procedures had a mortality (19%, 95%CI 13-28%), three times higher (3.0) than elsewhere in England (7%, 95%CI 5-8%) with 14.4 (95% interval 7-20) excess deaths among a total of 22 deaths.

- Among the 11 specific open procedure groups, mortality at UBHT for AVSD procedures (43%, 95%CI 22-66%) was four to five times higher (4.6) than elsewhere in England (9%, 95%CI 6-13%), with 7.0 (95% interval 3-9) excess deaths among a total of 9 deaths. Closure of ASD had mortality (63%, 95%CI 24-91%) which was over seventeen times higher (17.7) than elsewhere (4%, 95%CI 1-10%) with 4.7 (95% interval 3-5) excess deaths among a total of 5 deaths. No other procedure groups had a significantly high mortality.

- Closed procedures in this age group had the same mortality (4%, 95%CI 0-12%) as elsewhere (4%, 95%CI 2-6%).

Children aged 1 to 15 years

There were no classes of operations or procedure groups carried out at UBHT with a significantly higher mortality than elsewhere in England.

For all age groups combined, there were an estimated 32.9 (95% interval 9-49) excess deaths among a total of 69 in UBHT based on the open/closed class of operations and 35.3 excess deaths (95% interval 21-48) among a total of 67 in UBHT based on the 13 procedure groups.

There was a higher proportion of complications from surgery in admissions with open procedures in the UBHT than elsewhere in England with central nervous system complications mentioned in 1.6% (95%CI 0.7-3.1%) of admissions at UBHT compared to 0.4% elsewhere (95%CI 0.2-0.5%). This may be due to better recording of diagnoses at UBHT.

Analysis of length of stay of those children who survived their procedures showed a significant difference between length of stay at UBHT and elsewhere in England (open p=0.001, closed p=0.001). The main differences occurred in the first week. Following open operations, 2% of patients from UBHT were discharged within 7 days, compared with 27% elsewhere in England. For closed operations, 14% of patients from UBHT were discharged within 7 days, compared with 50% elsewhere in England. If discharges in the first week were excluded from the analysis, length of stay was not significantly different between UBHT and elsewhere in England.

Activity

There appears to be no reliable way of defining catchment areas for hospitals. Two definitions of catchment area were employed based on ***geographical*** proximity to each centre and ***empirically*** on where the majority of patients from each health authority were treated. These gave different estimates of surgical activity. We believe geographical proximity-based catchment areas are more useful in this analysis. Catchment areas for the London centres were particularly difficult to define because of their complicated referral patterns and their proximity to each other.

Overall there was a suggestion that activity rates were low in Bristol for open operations on residents within the catchment area, and this is supported by the numbers treated out of the area in other centres. However, the evidence for low activity rates is not compelling because of the difficulty in defining catchment areas.

Casemix and co-morbidity

Casemix and co-morbidity are important factors in determining outcome.

The age distribution for open procedures was different between UBHT and other centres, with a much smaller percentage of children in the under 90 days age group at UBHT (7%) compared to the rest of England (22%). For closed operations, the difference was less marked with 40% in the youngest age group at UBHT compared to 45% in the rest of England.

UBHT had very few ill-defined and unknown causes of morbidity and mortality (ICD9 799 codes) as the primary diagnosis compared with elsewhere, suggesting better diagnostic coding at UBHT.

Within the open category of procedures, there was a larger proportion of children with a diagnosis of Down’s syndrome in UBHT (10.3%, 95%CI 7.8-13.3%) compared with the rest of England (7.0%, 95%CI 6.4-7.5%). In the closed category, the difference between UBHT (4.1%) and elsewhere (2.9%) was not statistically significant.

In both open and closed procedures, UBHT operated on a smaller proportion of patients living in the most deprived areas with 11% of admissions falling into this category compared with 22% elsewhere. UBHT also had many fewer admissions with missing postcodes, again suggesting better recording of data.

From the limited amount of information available in HES data on casemix, it does not seem that the UBHT was operating on more severe cases, with the exception that there was an apparently higher proportion of Down’s Syndrome babies. This may be explained however by the apparent better quality of data recorded at UBHT.

Conclusions

These findings suggest that UBHT had a high mortality rate for open operations in children aged under 1 year, and particularly in children aged under 90 days. This rate is more than would be expected given the variation in mortality of the other centres. Data quality and casemix do not appear to explain these differences.

Table of contents

Glossary

95%CI	95% Confidence Interval
ASD	Atrial Septal Defect
AVSD	Atrial Ventricular Septal Defect
BRI	Bristol Royal Infirmary
CABG	Coronary Artery Bypass Graft
CIS	Clinical Information System
CMDS	Contract Minimum Data Set
COAD	Chronic Obstructive Airways Disease
DEPH	The Department of Epidemiology and Public Health at Imperial College School of Medicine, St. Mary's Campus
DHA	District Health Authority
DOB	Date of Birth
DH	Department of Health
DRG	Diagnosis Related Group
FCE	Finished Consultant Episode - *the time spent under the continuous care of a specific consultant*
HAA	Hospital Activity Analysis
HES	Hospital Episode Statistics
HIPE	Hospital Inpatient Enquiry
HRG	Healthcare Resource Groups
ICD	International Classification of Diseases
ONS	Office for National Statistics
OPCS	Office of Population Censuses and Surveys
OPCS4	OPCS Classification of Operation and Procedures, Fourth Revision
ORLS	Oxford Record Linkage Study
PAS	Patient Administration System
PEDW	Patient Episode Database for Wales
RHA	Regional Health Authority
TAPVD	Total Anomalous Pulmonary Venous Drainage
TGA	Transposition of Great Arteries
UBHT	United Bristol Healthcare NHS Trust – comprising the Bristol Royal Infirmary and the Bristol Royal Hospital for Sick Children
UKCSR	UK Cardiac Surgical Register
VSD	Ventricular Septal Defect

Foreword

The brief of the Bristol inquiry is to investigate the management of the care of children receiving complex cardiac surgical services at the United Bristol Healthcare NHS Trust (UBHT) – comprising the Bristol Royal Infirmary and the Bristol Royal Hospital for Sick Children - between 1984 and 1995 and relevant related issues. Clearly, as part of this inquiry, there is a need to examine routine sources of information to enable national comparisons between units, procedures and conditions. Hospital Episode Statistics (HES) are the major source of routine information on hospital activity available at a national level.

The Department of Epidemiology and Public Health (DEPH) at Imperial College School of Medicine, St. Mary's Campus has been commissioned to provide analysis of Hospital Episode Statistics and general statistical advice/consultancy to the Bristol Royal Infirmary Inquiry. This report gives an overview of hospital activity data quality, presents an analysis of HES data comparing mortality from paediatric surgical procedures at UBHT with procedures carried out elsewhere, and compares activity rates and casemix of patients with the rest of England.

1. Description and critical review of Hospital Activity Data

1.1. Introduction

1.1.1. The Bristol Royal Infirmary Inquiry terms of reference include the investigation of management of care of children receiving complex heart surgical services at the United Bristol Healthcare NHS Trust (UBHT) - comprising the Bristol Royal Infirmary and the Bristol Royal Hospital for Sick Children - between 1984 and 1995. The use of routine national hospital activity data (Hospital Activity Analysis – HAA – and Hospital Episode Statistics – HES) is one approach to determining the number of surgical procedures and the extent to which their outcomes differ from those in similar units. It is important that the limitations of the data are considered before interpreting such analyses. This section describes the history of national hospital activity data and explores relevant data quality issues.

1.2. History

1.2.1. Hospital Activity data have been collected since 1949 from all NHS hospitals.[1] Initially these were based on paper returns, which did not record age, sex or diagnosis. At the same time, a sample of NHS hospitals were invited to participate in the Hospital Inpatient Enquiry (HIPE) which did provide details such as age, sex, diagnosis and procedure for 10% of hospitals in England and Wales. This was published annually in the form of national tables. HIPE excluded psychiatric patients, as these were included in the Mental Health Enquiry. In 1962, there was a move to collect more comprehensive data from all NHS hospitals, and a Ministry of Health pilot scheme was initiated at St. Peter's Hospital in Chertsey. From 1969, the scheme was expanded to include all NHS hospitals and was known as Hospital Activity Analysis (HAA). HAA recorded discharges from and deaths in hospital. Processing of HAA was carried out on a regional basis. With the introduction of electronic data storage, HIPE was derived from a 10% subset of HAA, which was forwarded by regions to the Office of Population Censuses and Surveys (OPCS). HIPE reports were produced by the Department of Health and Social Security and OPCS.[2] The reports are in table form on paper and, in more detail, on microfiche. Discharges and deaths are broken down by region of treatment but there are no published tables, which also incorporate operation codes and age, essential for the BRI Inquiry. Archived HIPE datasets are now held by the Office for National Statistics (ONS) from 1962 to 1985.

1.2.2. Hospital Episode Statistics (HES) replaced HAA in 1987 and originated from the work of Edith Körner, an economist. The HES system attempts to measure all hospital inpatient activity for England (Wales has a similar system called the Patient Episode Database for Wales Data Set, or PEDW which replaced Welsh HAA in 1990). Unlike HAA data, the basic unit of the database is the Finished Consultant Episode (FCE), covering the period during which a patient is under the care of one consultant. Since 1991 it has been used for contracting in the internal market, and is a subset of the contract minimum data set (CMDS). It contains some ten million records per financial year.

1.2.3. The OPCS Classification of Operation and Procedures, Fourth Revision (OPCS4) was produced in response to the first report of the Steering Group on Health Services Information. It was originally intended that the new classification should be available for the commencement of coding for the HES system from the 1st April 1987. However the consultation process was longer than anticipated and so was absent from most of the 1987/88 HES data. The delay in disseminating OPCS4 to the NHS resulted in operations coding in HES during the 1988/89 year being an unusable mix of OPCS3 and OPCS4 codes. Several updates of amendments were issued between September 1987 and December 1989 with the intention that the NHS should implement the Consolidated Version 1990 of OPCS4, sometimes designated OPCS4R, from 1st April 1990 for the 1990/91 year onward. Implementation dates within hospital, district or regional coding systems were variable so that differing editions were employed by the NHS during the 1989/90 and to a lesser extent the 1990/91 HES year.

1.2.4. HES data are now held by IBM Global Services on behalf of the Department of Health (DH) and are available as data extracts or summary tables in several formats. Every NHS hospital in England (and Wales for PEDW) has to submit the forty or so data items of HES electronically for each FCE in every patient’s stay in that hospital to IBM (since May 1996 this has been through an NHS-wide clearing service called ClearNET). The data items are entered onto the hospital’s own computerised Patient Administration System (PAS) by trained clinical coders working with either patient notes from the ward trolleys or discharge summaries. These items include date of birth, sex, postcode of residence and clinical data such as primary and secondary diagnoses and dates and details of any operations performed within the patient's stay. Diagnoses are coded using the International Classification of Diseases (ICD) codes, often with the help of computer software. Clinical coding at this crucial stage is not subject to any external audit, and there is clearly scope for inter-coder variation[3 4] (see data quality section). IBM Global Services currently have data from 1989/90 available for extracts, but also hold 1987/88 and 1988/89 data on tape (personal communication). These would have to be loaded on to their system and cleaned before being made available for analysis.

1.2.5. As well as electronic returns, hospitals are obliged to submit paper counts (called KP70s) of patient episodes, which should be collected independently from the HES counts. DH use KP70 totals as the "gold standard" totals against which HES is compared. Discrepancies are investigated by DH, who contacts the provider concerned. HES data are then subject to a large number of automated validation checks by IBM, ensuring for example that all episodes have a provider and primary diagnosis code: this was not the case for the earlier HES years or for HIPE.

1.3. Data quality

1.3.1. The following section is a summary of the literature on data quality issues related to hospital activity data. There are three principal quality issues discussed: coverage, completeness and accuracy. Coverage refers to the proportion of the total activity recorded by a system. Completeness refers to the proportion of records that have an entry in any specified field. Accuracy refers to how far completed records reflect the true nature of the particular field. There was a paucity of literature on HAA data relative to the more recent HES system.

Coverage

1.3.2. For HAA, there was no equivalent of the KP70 returns and therefore no routine comparison data source, but a five-hospital study of proximal femoral fracture for the years 1977-78 identified cases from operation records and ward admission books and compared the numbers at each hospital with the number of cases recorded by HAA.

The discrepancies between the two totals varied very widely between the hospitals; at two hospitals the difference was less than ten out of more than a hundred cases, but, at another, only one case of proximal femoral fracture was obtained from HAA compared with 75 from operation records. Further enquiry at the hospitals suggested that an important reason for the poor coverage was inaccurate diagnostic coding by clerical officers associated with failure of clinical staff to complete diagnostic information on the relevant form. Although this study covers an earlier period than covered by the Inquiry, there is no reason to suspect that coverage changed until the Körner reforms in the mid 1980's. Assuming hospitals exhibit similar variation in coverage across England, comparisons between units using HAA will be difficult.

1.3.3. It is generally recognised that the change from HAA to HES caused widespread disruption in routine data collection for several years, with coverage, completeness and accuracy all adversely affected. This compromised data quality up to 1990/1 [5] and the following year was "generally considered to be more accurate and complete than previous years".[6] In a study that set out to investigate the effect of the change on the recording of hospital admissions for diabetes, data for 1987/8 were excluded from the analyses due to the known poor coverage for that year.[7]

1.3.4. Several authors described grossing and/or the comparison with KP70 counts. Williams[8] found that HES was nationally within 1.2% of the KP70 figure between 1989/90 and 1994/5, exceeding it for three of those years. For 1995/6, regional HES coverage (expressed as a percentage of KP70 counts) ranged from 95.1% in Anglia and Oxford to 100.7% (i.e. the HES total exceeded the KP70 total) for the South and West, with England as a whole having 98.3% coverage.[9] Sheldon et al.[6] stated that KP70s are "considered to yield the more reliable total number of episodes within a district" but rarely found substantial deviation from the HES totals.

1.3.5. There is a paucity of literature on the quality of recording of surgical procedures. A one-hospital study,[10] found that 14% of case notes had not been coded for either diagnosis or procedure and only 69% of endoscopies were recorded in 1989. Another study compared the number of deliveries recorded in maternity HES in 1990-91 with the number of registered births for the district of delivery.[11] There were maternity data for only 52% of deliveries. Two regions failed to submit any maternity data at all. Majeed and Pollock[12] observed that there were more reperfusions recorded in Wandsworth between 1990/1 and 1992/3 than there were angiographies - a clinical impossibility. These studies appear to contradict the favourable comparisons between HES and KP70, but call in to question the independence of the mechanism for KP70 collection. It seems likely that they are both subject to the same errors.

1.3.6. It is almost certain that some regular day-attenders (as opposed to patients having day case surgery) are misclassified as inpatients. It was discovered that in one district, one patient, with acute renal failure, had 192 episodes recorded in the same year.[13] A study of hospital admission and bed utilisation rates for diabetes between 1980 and 1990 found a dramatic increase in the first three HES years in admissions for diabetes with ophthalmic complications with a length of stay of less than one day.[7] While it is quite possible to be admitted for a duration of less than 24 hours, in this case it is indeed "overwhelmingly likely" in the authors' words that the majority of these admissions were actually day cases, not recorded by the former HAA, and not meant to be recorded as ordinary admissions by HES. However, this will not apply to the complex procedures addressed by the Inquiry, as they are unlikely to be day-attenders.

1.3.7. Some researchers have commented on the potential for "episode inflation" inherent in the internal market: purchasers are billed per episode, not per patient. This may affect analysis of episodes, but if the unit of analysis is hospital admission, this will be of less importance. A different problem is the fact that HES always excludes all private hospitals. This is of most numerical relevance in London, where nearly half of all private patients treated in NHS hospitals in England are found,[8] and this might have implications for comparing providers which perform specialist paediatric surgery outside the NHS.

Completeness

1.3.8. In data derived from HAA, 97% of Oxford record linkage study (ORLS) records had diagnostic data up to 1986.[14] Completeness was poorer in the early HES years as this figure dropped to 79% for the years 1987-1990 for that region. In another study one in seven ophthalmology codes were missing in four DHAs between 1987/8 and 1990/1.[15] A study looking at 1988 data found that the primary diagnosis code was missing for between 0 and 9% in a sample of two districts in each of eight regions,[16] whereas another study found this figure to be over 20% in East Anglia Region in 1990/1, though it was under 3% the following year.[17] Dixon et al[18] found that in North West Thames Region in 1993/4, 6.4% of episodes had no GP code and 9% had no clinical codes. Some Patient Administration Systems insert the vaguest ICD-9 code ('799') by default in the absence of any specified condition, thereby having fewer missing primary diagnoses but commensurately more meaningless vague codes.[19] In more recent years' data (for one London district for 1993/4) there were higher levels of completeness: less than 0.1% postcode, date of birth and sex fields were missing, but it "is possible (even probable) that some are incorrect." [20] In 1995/6, however, 22% of records in the Trent region had missing or invalid diagnoses: this was confined to a few Trusts and seems to have been due to the regional data processing system overwriting their clinical codes with 'R69' (ICD-10 code for unknown or unspecified diagnosis).

1.3.9. A descriptive analysis was carried out on the completeness of HES data years held by the DEPH. The department holds HES data from April 1st 1991 to March 31st 1996. Fields appear relatively complete with 100% completion for sex, age at start of episode, postcode and admission date. Primary diagnosis is 98% to 99% complete, which may be a good indication of how well completed the operation fields are. A separate analysis of an extract of episodes occurring in people aged below 16 years shows a similar level of completeness.

1.3.10. To check for valid postcodes, a postcode to enumeration district look-up file was used. If the postcode is not valid, then a null value is included on the record and this can be used as a way of validating the postcode. UBHT has high rates of completion suggesting that most postcodes are valid. However, because data are complete this does not necessarily mean high coverage or high accuracy. In any case, high completion rates are to be expected in these years of data, as prior to being incorporated into the main HES database, all submissions are subjected to a complex sequence of checks. Every record is interrogated – first to ascertain if it can be accepted (verification), then to determine whether inappropriate entries should be over-written (autocleaning) and finally an audit is carried out of the field contents so that a comprehensive set of quality reports may be generated (validation).[21] Reports are produced by the Department of Health for each trust.

Accuracy

1.3.11. Most studies that have investigated the accuracy of clinical coding relate to data collected before the 1990 NHS reforms, when incentives for quality were to some extent different and hospital information systems less sophisticated. Experienced clinical coders have generally not been used to review codes and were often not blind to the original codes.[4] In a study which compared recorded diagnoses with that from case notes identified from more than 2,000 Welsh HAA records for 1972/73 with diagnosed infectious disease, the diagnostic coding was incorrect in 19% of records, with diarrhoea and viral infections miscoded most often.[22]

1.3.12. In a study which examined the accuracy of operation codes on hospital activity analysis printouts in the North Western Regional Health Authority HAA covering the years 1975-80, it was discovered that inaccurate information was being provided in a significant number of cases. For example it was discovered that for splenectomy, 35 out of 109 (32%) procedures were incorrectly recorded by HAA. In an audit of coding of gastrointestinal endoscopy for 1989 HAA data in one hospital in Wales it was found that although the endoscopy unit kept its own records, none of the staff were initially aware of the coding system for endoscopic procedures for HAA.[10] Conventional typed discharge summaries were usually inadequate for coding purposes, and there was considerable variation in the proportion of procedures coded.

1.3.13. A more recent study focused on the reproducibility of clinical codes at two large acute hospitals within the former North West Thames (NWT) region between 1991 and 1993. It compared local and external coders (with at least four years' experience) and the most senior NWTRHA coding manager.[4] Procedure codes were investigated for first episodes. For the main procedure in one hospital, there was exact (four digit) agreement for 58% and approximate (three-digit) agreement for 70% (kappa=0.66). In the other hospital, the corresponding figures were 76% and 83% (kappa=0.80). The authors concluded that full clinical codes in HES should be treated with caution. The first three characters of the OPCS-4 codes were more reliable. A higher level of agreement in 1992/93 than in 1991/92 suggested that coding may be improving. As neither hospital had any unusual features, they concluded that the results were generalisable.

1.3.14. In a comparison of diagnosis coding Cleary et al. used experienced nurses with two weeks' intensive coding training to assess about 2,000 discharges from each of three hospitals, covering general medicine, surgery and maternity for 1990/1.[23] Computer records corresponding to the case notes were obtained by matching on the basis of hospital number and admission date, but at one of the hospitals the matching failure rate was 20%, indicating data entry errors in the matching criteria. For their sample of 501 matched records for which they assessed the primary diagnosis, in 51% the abstractors assigned an identical code to that computerised and in a further 39% they assigned a related diagnosis with a different code. These figures were enhanced by two study design considerations. In contrast to typical practice (DH, personal communication), the nurses used case notes rather than discharge summaries and were aided by the use of a clinical coding software package (Accucode II), which generates the required code from the medical terminology entered and the answers to a series of multiple choice. This may also help to explain why the nurses recorded many more secondary codes than given by the computer records.

1.3.15. In the North West Thames (NWT) study,[4] exact (four-digit) agreements on the main diagnosis were 41% at hospital A and 59% at hospital B, the figures for approximate (three-digit) agreement being 52% and 69% respectively. The third independent coder disagreed with both local and external coders in 53% of cases at hospital A and 38% at hospital B, with 1992/3 figures slightly more encouraging than 1991/2. Kappa statistics were calculated for two specific diseases, asthma and diabetes mellitus, which for hospital A were both 0.59 and for hospital B were 0.40 and 0.63 respectively. There were also inconsistencies when deciding to record asthma and diabetes as primary or secondary diagnosis. One in six asthma cases recorded by the local coders as secondary diagnoses in each hospital were believed by the external coders to be the main diagnosis, and about one in ten (9% at A and 14% at B) were not coded as either primary or secondary.

1.3.16. McKee et al.[16] observed that there are fewer secondary diagnoses and complications recorded in the UK than in the US, but acknowledged the financial incentive in the latter for clinicians to record co-morbidities more thoroughly, rather than place the patient in a less severe (and less costly to the purchaser) diagnosis related group (DRG). The idea behind the DRG was to group together lists of conditions which are homogeneous in terms of treatment costs, taking into account such considerations as length of stay.

1.3.17. In the UK in 1988 there was a greater use of vague codes such as “abdominal pain”, with concomitant less use of more specific codes such as appendicitis, compared with the US. [16] More recently it was concluded that the use of blanket terms for the first episode of a provider admission was especially likely in cardiology and geriatrics.[20] In contrast, Williams et al.[7] found a drop in admissions for “diabetes without mention of complications” in the first few years after the Körner reforms, and considered a partial cause of this to be improved recording of complications in discharge summaries, which are often used instead of patient notes for PAS entry.

1.3.18. As well as incorrect assignation of diagnostic codes, some authors questioned the veracity of entries for other fields. Carr-Hill et al.[24] and Sheldon et al.[6]omitted some wards due to the use of “dump” postcodes; this is their term for a default code, such as the postcode of the GP’s address, which is used when the patient’s postcode is unknown (HES demands this field not be left blank). Dumping of course leads to correspondingly low hospital use in neighbouring areas, and therefore Carr-Hill dropped a few wards with exceptionally low use as the only possible method of adjustment available to the authors (45 of 4985 wards were thereby dropped). Ben-Shlomo et al.[25] excluded 2.4% of their CABGs in the North East Thames Region in 1991 due to insufficient postcode information. The potential for error has also been noted when relatives give information instead of the patient.[26] Cleary et al.[27] found that their region’s maternity information system showed high levels of accuracy for administrative data, but there were problems when different definitions (e.g. of date of first assessment or of maternal infection) were used between different hospitals.

1.3.19. Analysis of time trends using hospital activity data is complicated by the change over from HAA to HES and the differences in HES data accuracy following the 1990 NHS reforms. One putative contributing cause of the apparent rise in asthma prevalence over the last few decades is that of diagnostic transfer.[17] The establishment of coding protocols and the tendency to code more wheezy conditions as asthma could explain some of the reported increase. One group excluded the under-5s and over-65s from their analyses because “cough and COAD may be mistakenly coded” as asthma in these age groups.[28] In terms of hospital admissions, rather than prevalence, the replacement of HIPE discharges and deaths with the FCE may also cause an apparent increase. This is because the former may not have included a diagnosis of asthma if, by the time of death or discharge, the patient died of or was being treated for another condition.

1.3.20. McKee summed up the poor reputation of routine data: “Many clinicians have concluded that, despite a massive investment in technology, routinely collected data still fail...and that separate systems are still required.” Many clinical departments have acquired their own Clinical Information Systems (CISs) and medical staff use these systems to produce discharge letters, to manage waiting lists and for other clinical office functions.[29] Such duplication of effort (by clinicians on CIS and medical records staff on PAS) is widespread. Walshe and colleagues were “disturbed” by the incompleteness of both systems - of the total number of cases they reviewed, the PAS data contained 92% while the CIS data contained only 77%.[30] Their study of the urology department of Brighton Health Authority also showed that PAS tended to record substantially more secondary diagnoses and procedure codes than the clinicians. With relevance to health service indicators, records of patients’ lengths of stay were less consistent than administrative details.

1.4. Conclusion

1.4.1. There are two sources of routine hospital activity data, which were collected during the period the BRI Inquiry is interested in (1984-95). HIPE covers the first two years of interest. Reports are available in table form on paper and, in more detail, on microfiche. Discharges and deaths are broken down by region of treatment but there are no published tables, which also incorporate operation codes and age, essential to the BRI Inquiry. Archived HIPE datasets are held by the Office for National Statistics (ONS) from 1962 to 1985. The 10% sample would be of very limited use to the inquiry because of small numbers and there would be great difficulty in retrieving and interpreting the original regional Hospital Activity Analysis data.

1.4.2. Hospital Episode Statistics data are held by IBM Global Services on behalf of the Department of Health (DH) and are available from 1989/90 to 1995/96. Earlier HES data are archived on tape, but have not been cleaned or loaded on to IBM Global Service's system. Because of patchy early implementation of coding for operations and procedures, and with many studies highlighting its poor quality immediately post Körner, HES data before 1991 would not suitable to inform the Inquiry.

1.4.3. For recent years (1991/92 onwards) it appears that HES data is a potential source of useful information, assuming data quality for individual sites is comparable to national quality. However, any analysis of HES has to be interpreted in light of its quality and should be considered in the context of other sources of information.

2. Outcomes of paediatric cardiac surgery at UBHT in comparison with the combined experience of paediatric cardiac centres in the rest of England

2.1. Introduction

2.1.1. The inquiry is investigating the management of care of children receiving complex heart surgery at the United Bristol Healthcare NHS Trust. This analysis examines outcomes in patient admissions in which one or more of a specific list of cardiac operations had been performed in children aged under sixteen. Hospital Episode Statistics (HES) contain information on every inpatient admission to NHS hospitals in England. They are based on finished consultant episodes where an episode is defined as the time spent under the continuous care of a specific consultant. If the primary responsibility for a patient is transferred from one consultant to another, a new episode will commence; the patient's stay in hospital – known as a "spell" or as we shall refer to it, an "admission" – will now comprise more than one episode. In order to derive outcomes from the data, episodes have had to be linked to admissions. An admission is deemed to have ended when the patient is "discharged". This may involve being discharged home, transferred to another hospital (provider) or death.

2.1.2. Each episode has up to four procedure fields coded to OPCS Classification of Operation and Procedures, Fourth Revision (OPCS4) which was produced in response to the first report of the Steering Group on Health Services Information.

2.1.3. HES data include a field for destination on discharge, which may for example be the patient's usual residence or another NHS provider; there is also a code to indicate that the patient died, although this doesn't include situations where the patient is discharged alive and dies elsewhere. Henderson et al.[31] looked at data from six health districts between 1979 and 1985, and found that 98.2% of hospital records which had specified that death occurred in hospital could be matched with corresponding death certificates; conversely, 94.4% of death certificates which specified that death occurred in hospital could be linked with abstracts of corresponding hospital inpatient records. They concluded that error rates are generally small.

2.1.4. In order to be able to count patients and admissions rather than episodes, for instance to calculate disease-specific readmission rates or determine outcome in a multi-episode stay in hospital, a unique patient identifier is required. National HES data up to the years 1996/97 do not have one, unlike the Scottish system. The NHS hospital number was introduced from 1997/98. Although complex matching procedures exist which rely on surname, forename, sex, date and place of birth, GP and address much of this data does not exist in HES. A description of the full procedure can be found in Gill et al.[32] With HAA and HES data, however, the best available method uses date of birth, sex and postcode to match records belonging to the same person, and this approach has been taken in several studies.[33 34] This has been found to be more than 90% accurate (L. Gill, personal communication), although it is possible for any of these variables to be wrongly recorded or for the patient's postcode to change legitimately from one episode or admission to the next. The same linkage process can be used to link admissions of care, using date of admission as a further identifier.

2.1.5. Mortality is one outcome of an operation, but there are other possible indicators of a poor outcome, which may be derived from HES data. This includes post-operative complications such as brain damage, renal failure and an extended length of stay in hospital. As well as the primary diagnosis, HES allows up to six further diagnosis fields, all using the ICD; it is not possible, however, to distinguish between pre-existing co-morbidity and iatrogenic disease.

2.1.6. This analysis uses HES data to compare outcomes from a selection of paediatric cardiac surgical procedures at the UBHT with the rest of England.

2.2. Methods

2.2.1. An extract of English Hospital Episode Statistics (HES) records was obtained from IBM Global Services containing records from 1991/92 to 1995/96 of patients aged under 16 who had undergone one or more operations with the code K* or L* (K is the OPCS4 Heart chapter and L covers Arteries and Veins). Other episodes were extracted by IBM that shared the same postcode, date of birth and sex fields. We first matched the IBM extract on postcode, date of birth and sex to give a patient identifier. Records were sorted on admission date to group episodes into admissions for each patient. Discharge date and episode end date were used to identify instances where the patient was re-admitted on the same date. For example, the episodes for a particular patient might look as follows:

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POSTCOD S DOB     ADMIDATE  DISDATE   DI  OPER1 OPER2 OPER3 OPER4
------- - --------- --------- --------- --  ----  ----  ----  ----
W2  1PG 2 09-FEB-92 28-APR-92               -   L121  L083  -     -
W2  1PG 2 09-FEB-92 28-APR-92 14-MAY-92 19  -   -     -     -
W2  1PG 2 09-FEB-92 21-MAY-92 23-MAY-92 19  K651  -     -     -
W2  1PG 2 09-FEB-92 14-JUN-92 16-JUN-92 79  K061  K111  K104  -
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where DI is the discharge destination or outcome, 19 representing discharged home and 79 representing death, and OPER1-4 are the four operation code fields. In the above example there are three admissions, the first two episodes would form a single admission but each of the last two would be classified as separate admissions. In this example it can be seen that without linking episodes across admissions the discharge outcome associated with the operations L121 and L083 would be lost. The admission was deemed to have ended in death if either of two fields, DISTDEST or DISTMETH, had indicated this.

Procedure groups

2.2.2. A set of 13 procedure groupings were devised after taking wide-ranging advice from a number of clinical experts in this field. A draft grouping proposed by the casemix programme at the NHS Information Authority made up of 22 groups procedures was circulated to an expert panel of paediatric cardiac surgeons for comment. This led to exclusion of some procedures considered to be irrelevant and refinement of the groupings down to 17 groups. Further consultation with the surgeons and cardiologists reduced these to a final 13 groups (table 2.1).

2.2.3. Selection was based on any mention of the procedure codes of interest in any of the four operation fields available on HES. This was because, unlike the diagnostic fields where hospitals have to put the primary diagnosis in the first diagnosis field, guidance is less clear on putting the main procedure in the first operation field (personal communication with Statistics Division, DH).

Rankings

2.2.4. There are admissions where more than one procedure has been carried out. In order to assign each admission to only one of the 13 procedure groups, it was necessary to select a "primary" procedure. A list of common combinations (those occurring nationally more than 20 times during the analysis period) was sent to a member of the expert surgical group who was asked to indicate the primary operation in each case. From this, a ranking system was derived, ordered to place open procedures above closed and to take into account national mortality rates. These rankings were used to select one primary procedure for each admission and are shown in table 2.1.

Open/Closed Classification

2.2.5. An additional set of groupings based on whether procedures were open or closed was also derived. An open operation is one in which the heart needs to be stopped and the patient put on a heart lung machine. A list of procedures was derived from common activities carried out at the United Bristol Healthcare NHS Trust. The list of OPCS4 procedure codes were reviewed by a paediatric cardiologist, a paediatric cardiac surgeon and a national coding expert and were classified into either open or closed. Medical procedures, diagnostic procedures or procedures that were difficult to define were excluded from the analysis. The codes are listed in the Appendix.

2.2.6. Admissions with any mention of any of the operations in each group were identified both nationally and for United Bristol Healthcare NHS Trust. Using the procedure group ranking and the open/closed classifications, each admission was assigned to one of the 13 procedure groups and classed as either open or closed.

2.2.7. Because of the different way that the various procedure groups, and open/closed classes were defined, there are slight differences in the two classifications. For example, there are 15 admissions included in groups 1-11, classified as open procedures (table 2.1), but which are classified as closed in the open/closed classification given in the Appendix.

Outcome

2.2.8. Mortality was defined as death within 30 days of the primary procedure, thus if the patient lived for more than 30 days, the patient was deemed to be alive regardless of the final discharge destination. Patients with discharge within 30 days or where length of stay could not be calculated were assigned one of three outcomes; for discharge home or transfer to another hospital, outcome was alive, death discharges were recorded as dead and admissions where the outcome was unknown were excluded from the denominator. After consultation with a member of the expert panel of paediatric cardiac surgeons, outcomes were derived for three age groups (under 90 days, 90 days to under 1 year and 1 to 15 years). These age groups were also consistent with a risk stratification exercise for paediatric cardiac surgery carried out in the US.[35]

2.2.9. In order to maintain some comparability with other data sets, the time period covered by the inquiry has been divided into epochs. HES data considered here span two epochs, 1st April 1991 to 31st March 1995 (epoch 3) and 1st April 1995 to 31st December 1995 (epoch 4). Because the two surgeons at the UBHT had stopped much of their complex cardiac paediatric surgery by the end of March 1995, this report refers mainly to epoch 3. Annual mortality rates have been produced however to illustrate time trends in mortality at the UBHT which include epoch 4.

2.2.10. All of the diagnosis fields within the open and closed categories were searched to identify complications such as brain damage or renal failure during or resulting from a procedure.

2.2.11. The length of stay was determined from the date of admission to the discharge date (if available).

Statistical methods

2.2.12. Our aim was to compare the death rates for operations at UBHT with those in the rest of the England. For all procedures groups and classes in each age group we calculated mortality rates for UBHT and all other centres combined. We also calculated the ratio between them.

2.2.13. However, even if there were no true difference between the death rates in UBHT and the rest of England, it could happen that the mortality rate calculated from a particular limited sample of cases differs from the national rate by chance. We therefore assessed whether a mortality rate is "significantly" different from the national rate by calculating 95% confidence intervals. This is a range of values around our computed mortality rates: if the 95% confidence intervals do not overlap, we can be confident that the difference in mortality is unlikely to be due to chance.

2.3. Results

2.3.1. A total of 216,832 episodes were identified from the IBM Global Services extract consisting of all episodes with STARTAGE less than 16 (figure 2.1) occurring between 1st April 1991 and 31st March 1995 that either contained a mention of K* or L* codes in any of the operation fields or that were matched (via DOB, sex or postcode) to these episodes. Of these, 41,529 admissions had a mention of K and L codes, 1,910 were in UBHT and 39,619 were in the rest of England. There were 758 admissions in UBHT that had procedures either belonging to one or more of the 13 groups or the open/closed classes. The figure was 11,194 in the rest of England. Overall, 18% of admissions had more than one procedure from the 13 procedure groups and for these, the ranking table was used to determine primary procedure.

2.3.2. Tables 2.2 to 2.4 give numbers of surgical procedures and deaths for UBHT and for the other centres in England with mortality for each of the three age groups, using the 13 procedure groupings described in table 2.1 and the open/closed classification. Figures 2.2 to 2.4 show these results graphically.

Mortality

2.3.3. For children aged less than 90 days (table 2.2, figure 2.2), open procedures in UBHT had a mortality (63%, 95%CI 44-80%) nearly four times higher (4.0) than that elsewhere in England (16%, 95%CI 14-18%). Among the 11 specific open procedures, switch (other operations for Transposition of Great Vessels, TGA) procedures had a mortality (90%, 95%CI 55-100%) which was nine times higher (8.9) than elsewhere (10%, 95%CI 8-13%). Some of the other procedures (groups 2, 5, 8 and 10) had mortality rates of 100%, but the small numbers (1 or 2 cases in each group) meant it was difficult to draw any conclusions about them. Closed procedures in this age group had the same mortality (5%, 95%CI 2-12%) as elsewhere (5%, 95%CI 4-6%).

2.3.4. For children aged 90 days to under one year (table 2.3, figure 2.3) there are also variations in mortality outcomes between procedural groups. Open procedures had a mortality (19%, 95%CI 13-28%), three times higher (3.0) than that elsewhere in England (7%, 95%CI 5-8%). Among the 11 specific open procedure groups, mortality at UBHT for AVSD procedures (43%, 95%CI 22-66%) was four to five times higher (4.6) than elsewhere in England (9%, 95%CI 6-13%). Closure of ASD had mortality (63%, 95%CI 24-91%) which was over seventeen times higher (17.7) than elsewhere (4%, 95%CI 1-10%). No other procedure groups had a significantly high mortality in this age group. Closed procedures had the same mortality (4%, 95%CI 0-12%) as elsewhere (4%, 95%CI 2-6%).

2.3.5. For children aged 1-15 years, there were no significantly elevated mortality rates for any of the 13 procedure groups or the open/closed categories.

Annual mortality

2.3.6. An analysis of annual numbers of admissions and deaths among children aged less than 1 year suggests that mortality from complex cardiac paediatric surgery at UBHT had been substantially reduced by the end of December 1995. Figure 2.5 of annual mortality rates shows mortality decreased from 29% (95%CI 15-47%) in 1994/5 to 4% (95%CI 0-22%) in the last 9 months of 1995 for open procedures.

Complications

2.3.7. There was little difference in the average number of diagnoses per admission for open and closed operations in UBHT (4.2) compared to in the rest of England (4.0). Complications were recorded in a higher proportion of all admissions in UBHT than elsewhere in England (table 2.5 and table 2.6). Central nervous system complications are mentioned in 1.6% of admissions with an open procedure in UBHT, 4 times more than elsewhere.

Length of stay

2.3.8. Among children who survived their procedures, there was a significant difference between length of stay at UBHT and elsewhere in England (open p=0.001, closed p=0.001). The difference was especially apparent in the first week. Following open operations, only 2% of patients from UBHT were discharged within 7 days, compared to 27% elsewhere in England. For closed operations, 14% of patients from UBHT were discharged within 7 days, compared to 50% elsewhere in England. If discharges in the first week are excluded from the analysis, length of stay is not significantly different between UBHT and elsewhere in England.

2.4. Discussion

2.4.1. The picture emerging from these results is that there was higher mortality in children aged under 1 for some procedures carried out in UBHT between 1st April 1991 and 31st March 1995. In open operations, mortality was significantly higher in UBHT than elsewhere in England, particularly in those aged under 90 days. Switch operations in particular appeared to have high mortality in this age group.

Groupings

2.4.2. Two sets of procedure groupings were used in this analysis: The thirteen specific procedure groups and a broader classification of either open or closed operations. There are a number of reasons for grouping procedures:

- To enable comprehensive analysis of all paediatric cardiac operations with a manageable number of categories
- To enable sufficient volumes of cases for statistical robustness in comparisons of mortality rates, whilst still allowing adjustment for the different mortality rates expected from the different procedures
- To allow a broad comparison of the variations in casemix between providers by looking at the volume of cases within each grouping
- To allow comparison across different data sets.

2.4.3. Two different classification systems for the types of procedures undertake were used in this study, which were arrived at in different ways.

2.4.4. ***Operation procedure groups.*** It was difficult to get complete agreement from the paediatric cardiac surgeons advising us on the 13 procedure groups devised for this study. Any grouping is likely to elicit some disagreement, but groups were eventually arrived at after three rounds of consultation with surgeons. Comparability with other data sources was an important consideration and 12 out of the 13 groups map to the UK Cardiac Surgical Register (UKCSR) procedures. Groups 1 to 11 were considered by the expert group to be *open* procedures, while groups 12 to 13 were *closed*

2.4.5. ***Open/closed classification.*** The much broader open/closed classification was originally derived from examination of a list of codes used on the PAS data at the United Bristol Healthcare NHS Trust in discussion with a cardiologist and a paediatric cardiac surgeon. Some OPCS4 codes were not mentioned on the original list, but nevertheless appear in the 13 procedure groups. There are therefore examples of admissions (309 in total, see figure 2.6) which are excluded from the open/closed classification, but which are included in the 13 procedure groupings (222 in groups 1-11, 87 in groups 12-13). There are also 15 admissions within the closed class (0.4%) which also appear in the open procedure groups (groups 1-11) while there are 172 admissions within the open class of procedures (2.1%) which also appear in the closed procedure groups (groups 12-13). However, excluding the 172 cases that appear both in the open class and groups 12-13 does not appreciably alter the mortality for the open class of procedures.

2.4.6. Because the open/closed classification was based on the UBHT list of procedures only, there will not be complete correspondence with a similar classification derived from the UKCSR.

Data quality

2.4.7. We investigated the possibility that poor data quality could account for the statistically higher mortality rate in open operations in UBHT. A number of patient matches were made incorrectly. A number of “bucket” postcodes were found, which are used by hospital coders when the real postcode of residence is not available. These make a match more likely by reducing the number of possible combinations of postcode, date of birth and sex. Same-sex identical twins will automatically be matched as the same patient. However, because the analyses were carried out using admission data and the admissions were additionally matched on admission date, these problems were minimised.

2.4.8. Differences in the coding of outcome between UBHT and the rest of England could affect the mortality rates. Outcome is also dependent on accurate matching of episodes to admissions. On some occasions an admission did not appear to have an end date and therefore the outcome is unknown. There are a number of reasons for this. Firstly, the discharge information may simply not have been added to the last episode. Secondly, and possibly more likely, is that an error in entering any of the postcode, date of birth or sex fields would result in a failure to link all the correct episodes to the same patient. Thirdly, in a small number of cases an admission may have started but not finished because it occurred at the end of the data period being analysed. Taken together, these three data issues resulted in a number of admissions with a missing outcome. For example for open and closed procedures carried out at UBHT in children aged below 90 days, 19% and 3% of admissions had no outcome recorded, compared with 3% and 1% of admissions elsewhere. If the admissions with unknown outcomes had a different mortality to admissions with outcomes that are known, then it might bias our calculated mortality rates. In order to estimate the possible extent of this bias, the most extreme case of bias was considered for mortality in open procedures. Missing outcomes were attributed to being alive at 30 days for admissions in UBHT, and attributed to deaths for procedures carried out elsewhere in England. The mortality remained significantly higher than the national rate, changing from 63% (95% CI 44-80%) compared to 16% (95% CI 14-18%) in the rest of England to 51% (95% CI 34-68%) and 19% (95% CI 17-21%) respectively.

Complications

2.4.9. Although there are a higher proportion of complications in UBHT admissions than elsewhere in England, UBHT also records more diagnoses per admission generally than elsewhere in England (4.2 diagnoses per admission compared to 4.0 per admission). We also know that UBHT is less likely to use vague diagnoses such as "Other ill-defined and unknown causes of morbidity and mortality" (ICD9 799). This suggests that diagnostic information in HES records from UBHT is more complete than elsewhere and may explain the higher reporting of complications. It is also not known whether complications were present before or after the procedure in question.

Length of stay

2.4.10. Length of stay may be complicated by several factors. If episodes cannot be linked together to form a complete record of admission, then length of stays will appear shorter. If a patient dies during an admission, then that would also tend to shorten the length of stay. We have excluded deaths and outcomes, which are unknown from our analysis and include discharge to normal or temporary residence only.

Between centre variation

2.4.11. This analysis takes some account of the possible chance variability of mortality rates at UBHT and for centres in the rest of England by providing 95% confidence intervals. A full investigation requires proper adjustment for chance variability in each of the other specialist centres in England. While we have allowed for chance variation in the average of the national mortality rates of all the other centres combined, there may be additional variability in mortality rates between centres, because of small numbers, that has not been taken into account. In Section 3. We refine the analysis to include between centre variation.

Casemix

2.4.12. Differences in mortality rates between different centres may be partially explained by differences in severity of cases or casemix. HES provides no information on severity of cases, and there is limited information on casemix in the HES database. The underlying diagnosis and severity, co-morbidity, sociodemographic characteristics of the patient such as ethnicity and social class, and other factors which may contribute to variations between centres in the health of the patients prior to admission may all be important determinants of outcome. Some attempt to compare co-morbidity and sociodemographic factors of UBHT patients relative to the other centres is presented in Section 5.

2.4.13. In conclusion, there is evidence of a higher mortality in some procedures carried out at the United Bristol Healthcare NHS Trust in patients aged under 1 year old. For "open" procedures carried out in babies less than 90 days, the mortality rate was 63% (95% CI 44-80%), four times higher than that elsewhere in England (16%, 95%CI 14-18%). There is also, in addition, a suggestion of a higher complication rate in procedures carried out in the UBHT, but this could be explained by their apparent higher quality recording of diagnosis.

3. Comparison of outcomes for individual centres carrying out paediatric cardiac surgery in England

3.1. Introduction

3.1.1. Performance measures such as surgical mortality rates at different centres will vary for at least three reasons: (i) due to random variation, (ii) due to the nature and quality of care they provide, and (iii) due to variation in the health of their respective patients prior to admission (the latter is often termed the ‘case mix’). One of the purposes of this inquiry is to assess whether UBHT is a genuine outlier in terms of the quality of care provided relative to other specialist centres, or whether its performance appears extreme due to random variation. A full investigation of this question therefore requires proper adjustment for the role of chance and case mix in determining performance in each of the specialist centres carrying out cardiac surgery in children in England.

3.1.2. This analysis aims to address the first of these issues by using statistical methods, which adjust for chance variations between centres. Any remaining differences in mortality rates between UBHT and the other centres may then be reasonably assumed to arise due to systematic differences in some combination of the case mix and quality/nature of care provided by UBHT relative to other centres. Unfortunately, it was not possible to adjust for case mix in this analysis since there is limited information in the HES database on the underlying diagnosis and severity, co-morbidity, sociodemographic characteristics of the patients such as ethnicity and social class, and other factors which may contribute to variations between centres in the health of the patients prior to admission. Some attempt to compare co-morbidity of patients and sociodemographic factors of the catchment populations for UBHT relative to the other centres is presented in Section 5. However, it is important to remember that no adjustment has been made for case mix when interpreting the results of the analysis presented in the current section.

3.2. Methods

3.2.1. In order to address the question of whether UBHT is a genuine outlier or simply appears extreme due to chance, we first estimated the mortality rate for a typical or average centre based on the rates observed in the 11 centres excluding UBHT. This estimate takes the form of a *distribution* giving the relative probability of possible ‘true’ values for the typical mortality rate. The distribution reflects our statistical uncertainty about this quantity due to random variation in the observed mortality rates from which it was estimated. Bayesian hierarchical methods [36] were used to estimate this distribution for each procedure and age group; full details are given in the Appendix.

3.2.2. We then compared the distribution of expected mortality rates for a typical centre with the mortality rate in UBHT. Since the latter also exhibits random variation, we again represent our statistical uncertainty about the ‘true’ rate in UBHT by a probability distribution. The extent to which the distribution of mortality rates in UBHT differs from the distribution of mortality rates expected in a typical or average centre reflects the extent to which UBHT may be viewed as a genuine outlier.

3.2.3. We can quantify the difference in performance between UBHT and a typical centre by predicting the number of deaths expected in UBHT if the typical mortality rate applied there, and comparing this to the observed number of deaths. The quantity

excess deaths = (observed deaths – predicted deaths)

estimates the number of deaths in UBHT in excess of that expected based on the typical performance of the other 11 centres in England. This estimate takes into account random variation in mortality rates between the other 11 centres plus sampling variability in the observed number of deaths in UBHT given its ‘true’ mortality rate.

3.2.4. One of the remits of this inquiry is to consider how the performance of *each* of the 12 specialist centres compares to the others, rather than focusing only on UBHT’s performance relative to the remaining 11 centres. We therefore repeated the above analysis for each centre in turn, i.e. for each procedure and age group, we estimated the excess number of deaths in each centre using the expected mortality rate predicted by the other 11 centres. So doing allows us to better put into context the number of excess deaths estimated for UBHT.

3.2.5. In a separate analysis we ranked each of the centres according to their observed mortality rate for each procedure and age group. However, comparison of the observed ranks is misleading, since one centre will always be ranked worst, and this takes no account of chance variations in mortality rates between centres. The latter point is particularly relevant when the observed mortality rates are based on small numbers. Therefore we also estimated the statistical uncertainty associated with each rank using a Bayesian simulation method described in the Appendix. This method allows us to calculate 95% intervals for the ranks: each interval is a range of values within which we are 95% sure the 'true' rank for that centre lies. Using this method, we can also calculate the *probability* that each centre is ranked worst. This probability takes into account the observed mortality rate in each centre relative to the others, but acknowledges that observed rates which are based on small samples may be very imprecise estimates of the underlying 'true' mortality rates.

3.3. Results

3.3.1. Tables 3.1 and 3.2 show the results of the excess mortality and ranking analyses for the 13 procedure groups and the open and closed class of procedures in each age group in UBHT relative to the other 11 centres. Observed mortality rates with actual numbers of admissions and deaths are given for UBHT and summed over the other 11 centres. We then report the expected number of deaths in UBHT based on the typical mortality rate estimated from the other 11 centres. The excess deaths column is given by the difference between observed and predicted deaths in UBHT; as with any statistical summary measure, the excess deaths in UBHT has associated uncertainty, and so we also report a 95% interval for this number. This is a range of values around our estimate of the excess deaths which we are 95% sure contains the true number of excess deaths. Note that if the typical mortality rate (and hence the predicted number of deaths) is *higher* than that observed in UBHT, the number of excess deaths will be *negative*, indicating that UBHT had fewer deaths than predicted based on the mortality rates in the other 11 centres. We also calculated the probability that the number of excess deaths in UBHT was greater than zero (i.e. the probability that there were more deaths than predicted). The final four columns of tables 3.1 and 3.2 show the results of the ranking analysis. The first of these gives the number of centres carrying out procedures for each procedure and age group (this does not necessarily include all 12 centres). The next two columns show where the observed mortality rate in UBHT ranks out of these centres, together with a 95% interval for the rank of the 'true' mortality rate in UBHT after allowing for uncertainty associated with the observed rank. The final column reports the probability that the 'true' mortality rate in UBHT is ranked worst out of all the centres. In total there are 35.3 total excess deaths out of 67 in UBHT (95% interval 21-48) based on 13 groups and 32.9 total excess deaths out of 69 in UBHT (95% interval 9-49) based on open & closed groups. We can be more than 95% certain that there was a positive excess mortality in UBHT for procedure groups 3 and 4 and open procedures in children aged under 90 days, and groups 5 and 6 and open procedures in children aged 90 days to under 1 year. UBHT was also ranked worst for 6 of the 10 procedure groups plus open procedures carried out in children aged under 90 days; 6 out of 13 procedure groups plus open procedures carried out in children aged 90 days to under 1 year; and 1 out of 12 procedure groups carried out in children aged 1 to 15 years. However, statistical uncertainty due to the small number of admissions upon which these mortality rates and ranks are based means that we can be greater 95% certain that UBHT ranks worst only for open procedures in children aged under 90 days. We are also between 90% and 95% certain that UBHT is genuinely ranked worst for procedure group 3 in children aged under 90 days, and for open procedures in children aged 90 days to under 1 year.

3.3.2. The top left graph in figure 3.1 shows the probability distribution for the typical mortality rate for open procedures in children aged under 90 days estimated from the 11 centres excluding UBHT (shaded in solid grey). The probability distribution for the 'true' mortality rate for open procedures in children aged under 90 days in UBHT is shown on the same graph using hatched shading. As already noted, the discrepancy between these two distributions is formally quantified by the estimated number of excess deaths for open procedures in children aged under 90 days in UBHT (see table 3.2). The remaining graphs in figure 3.1 show equivalent plots for open procedures in the two older age groups, and for closed procedures for all three age groups.

3.3.3. Table 3.3 summaries the results of repeating the excess deaths analysis in each of the 12 centres. The table shows the number of excess deaths in each centre and procedure group for each age group separately, and for all ages combined. To acknowledge the statistical uncertainty associated with each of these estimates, the cells in the table are shaded according to the probability that the number of excess deaths shown in that cell is greater than zero. Grey shading indicates that we are at least 95% certain that there was positive excess mortality for the relevant centre, procedure and age group; unshaded cells correspond to those centres, procedures and age groups for which there was a negative excess (i.e., there were fewer deaths than predicted) or for which we are less than 95% sure that there was a genuine positive excess. There is one other centre for which we are greater than 95% sure that there was a positive total excess number of deaths. At all ages (0-15 years) centre 10 had 27.7 excess deaths based on groups 1-13 and 31.8 excess deaths based on the open and closed classes of procedures. In contrast to UBHT, where most of the excess deaths occurred in children under 1 year, this excess came mainly from procedures in children aged 1 year and older, and was for both open and closed procedures.

3.3.4. When each of the centres were ranked according to their observed mortality rate for each procedure and age group, we could be 95% sure that open procedures at UBHT were ranked as having the worst mortality. We were also at least 95% certain that centre 10 had the worst ranking for open procedures in children aged 1 to 15 (not shown in the tables).

3.4. Discussion

3.4.1. These findings confirm the findings of the previous section that UBHT has a high mortality rate for open procedures in children aged under 1 year; this is more than would be expected given the variation in mortality of the other centres.

3.4.2. A key difference between the analyses presented in this section and the previous section concerns the way in which the ‘reference’ mortality rates are defined (i.e. the national standard against which UBHT’s performance is being compared). In Section 2, we pooled data from the other 11 centres to obtain an estimate of the overall mortality rate for each procedure and age group. These reference rates can be interpreted as the risk of dying for a typical child treated in the rest of England excluding UBHT. By contrast, the analyses carried out in this section treat each of the other 11 centres individually, i.e. the units of analysis are the 11 centres rather than the individual children treated in each centre. This method allows us to pool information on mortality rates across centres thus improving the accuracy of our estimates. The resulting estimate of the overall mortality rate is interpreted as the risk of dying for a child treated in a typical centre excluding UBHT, rather than for a typical child treated at any one of the 11 other centres. Given the remit of the inquiry to understand the nature and outcomes of children's heart surgery at UBHT relative to the other specialist centres, an analysis comparing mortality rates in UBHT to those of a typical centre elsewhere in England is the most appropriate approach. The concordance of the pictures emerging from this analysis and from the comparison of UBHT's mortality rates with those estimated for a typical child in Section 2 lend further credibility to the results.

3.4.3. One of the problems with this kind of analysis is that it can be sensitive to the statistical assumptions used in the calculations. We carried out a range of analyses using various modelling assumptions and found that the final conclusions concerning excess mortality in UBHT were unchanged (see Statistical Appendix for further details).

3.4.4. One other centre (Centre 10) as well as UBHT stood out as having a large excess of deaths. These occurred mainly in children aged over 1 year in both open and closed procedures. The total number of excess deaths for all ages was 31.8, which is comparable to the 32.9 excess deaths in UBHT. As in UBHT, the excess in Centre 10 may be due either to differences in case mix or to the nature and quality of care the centre provides. We examine case mix and co-morbidity for UBHT in section 5, but it is beyond the remit of this report to look at these factors for other individual centres. Therefore the results for Centre 10 should be interpreted with caution.

3.4.5. With so many different analyses (12 centres, 13 procedure groups, the open/closed class of procedures and 3 age groups) it is possible that some statistically significant results might arise by chance (here we take 'statistical significance' to mean any finding where we are over 95% sure that there is a positive excess). However, one of the reasons for carrying out the excess deaths analysis for all 12 centres rather than just UBHT was to help place the results for UBHT in context. If the excesses found in UBHT were just due to chance, then we would expect to see a similar number of 'statistically significant' excesses in other centres, which was not the case. That the cumulative excess of deaths for all ages and procedures is also ‘statistically significant’ in UBHT strengthens our belief that this result is not merely due to chance.

4. Activity and referrals

4.1. Introduction

4.1.1. The Inquiry commissioned a comparison of levels of surgical activity at the United Bristol Healthcare NHS Trust with those at other centres in England. In order to look at admission rates, a suitable denominator population has to be identified, a catchment area. Information was obtained on administrative catchment areas but was ill defined and inconsistent with our observations. For example, South West Devon falls within the old style South Western Region, yet over half of its patients are treated at Southampton. Moreover, we did not have access to administrative catchment areas to other centres. As an alternative, we defined catchment areas in two ways:

- **Geographical**: by proximity to each centre
- **Empirical**: by where the majority of patients from each HA were treated.

4.1.2. The BRI Inquiry also asked us to look at referral patterns to UBHT and compare them to other centres. HES contains information on inpatient episodes only and does not record outpatient attendance or referral. However, for those people who are admitted to hospital and undergo a procedure, their place of residence can be ascertained through their postcode of residence. This gives a means to identify where people lived who were treated and hence can be used as a proxy for *referrals*.

4.1.3. This section therefore looks at activity rates by catchment area and compares the proportion of people treated within their catchment areas with the proportion treated outside their catchment areas. The question of different *referral* patterns according to differing socio-economic status has also been addressed.

4.2. Methods

Geographical proximity-based catchment areas

4.2.1. Geographical Information Software was used to determine the distance from the population centroid of each HA (1996 boundaries) to each specialist centre. Each HA was then allocated to the nearest specialist centre catchment area.

Empirical activity-based catchment areas

4.2.2. The number of admissions from each HA (1996 boundaries) to each specialist centre was calculated for the 13 procedure groups combined and from the open or closed classes. Each health authority was then allocated to a specialist centre catchment area, according to the centre which undertook the largest proportion of operations of residents within that HA.

Activity levels

4.2.3. Activity rates for open and closed operations were calculated for each catchment population, based on live births for children under one year and 1993 mid-year population estimates for children aged 1 to 15 years. For each catchment area, three indicators were calculated.

- **Centre activity**-the activity rate by each specialist centre on its own catchment area population

- **Catchment activity**-the activity rate for each catchment area including all operations carried out in England on the resident population regardless of where the procedure was performed

- **Flow ratio**-The ratio of the number of admissions exported from the catchment area (i.e. procedures performed on the catchment residents by another centre) to the number of admission imported (i.e. procedures performed on children from out of the catchment area by the 'home' centre)

4.2.4. Those treated at a centre for whom postcode and hence area of residence were unavailable were excluded from the analysis. Welsh residents were also excluded because we did not have access to Welsh hospital activity data and were therefore unable to determine the Bristol catchment area in Wales. If Welsh residents treated at UBHT had been included in the analysis without including the catchment population, the resultant activity rates would have been spuriously high. Cardiac congenital anomaly rates were calculated for each geographical catchment area the using the National congenital anomaly register and Office for National Statistics data on the numbers of live and still births.

Referral patterns and socio-economic deprivation

4.2.5. A socio-economic deprivation score was assigned to each admission by matching postcode with 1991 census information at enumeration district (ED) level. The Carstairs deprivation index[37] was used (components are social class IV & V, car ownership, unemployment and overcrowding). Scores at ED level have been ranked into quintiles and it is these quintiles that were used in the analysis.

4.3. Results

4.3.1. Figures 4.1 and 4.2 are maps showing the boundaries of catchment areas defined by geographical proximity and activity levels. The London centres are not contiguous, reflecting the varied referral patterns experienced by these centres and we therefore decided to treat them, for the purpose of this analysis as one centre. Tables 4.1 to 4.4 give the three activity indicators for each of the specialist centres and their catchment areas by age (under 1 year and age 1 to 15 years) and by class of procedure (open or closed). In addition, the total number of admissions for the target procedures by each specialist centre and its catchment population are shown.

4.3.2. Twelve percent of admissions had unknown postcodes and were excluded from the activity analysis. Of these, 48% were treated at Great Ormond Street and 19% at the Brompton. Only 0.5% were treated at UBHT.

4.3.3. The 'geographical' and 'empirical' catchment areas are broadly similar and for Birmingham and Newcastle are identical. But where differences exist, they can change the results substantially. For most centres their catchment areas differ by one or two HAs only. The Bristol geographic catchment area includes Wiltshire and SW Devon HA in addition to the five empirical activity-based HAs. Of these 'marginal' HAs, 36% of admissions were treated at UBHT, 39% at Southampton and 16% at Oxford. These two HAs therefore affect the flow ratios substantially. For residents in the whole geographic catchment area, 69% went to UBHT (table 4.5).

Centre Activity

4.3.4. For centre activity of some centres (UBHT, Leicester, Leeds), geographical proximity-based catchment areas tended to give a lower rate than the activity based catchment areas. In children under one year, based on geographical catchment areas, the rate for admissions which included open procedures for UBHT was 0.72 per 1000 live births per year (the lowest rate for all the centres), compared to 0.88 per 1000 based on empirical catchment areas, the second lowest rate. For closed operations under one year, for geographical catchment areas, Bristol had an unremarkable rate of 0.62 per 1,000 live births per year, while for empirical catchment areas Bristol had the second highest rate (0.77 per 1,000 live births per year).

4.3.5. For children aged 1 to 15, for both geographical and empirical catchment areas, UBHT had unremarkable procedure rates on its own residents.

Catchment activity

4.3.6. Catchment activity rates were similar using both the geographic and the activity definitions of areas. Bristol's rates were unremarkable in comparison with the other centres.

Flow Ratios

4.3.7. Under the geographical proximity-based catchments, Bristol has either the highest or (in one case) the second highest flow ratio, i.e. there is an apparently high net export of admissions from the Bristol catchment area. To some extent this may reflect a net inward flow of Wales, which has been excluded from these calculations. For open procedures in children aged under 1 year, UBHT is unique amongst the centres in having no admissions from outside the catchment area. With the empirical activity catchment areas, Bristol has an unremarkable flow ratio, with a ratio for open procedures in children aged under 1 year of 2.1 (41 out, 20 in). Figure 4.3 shows the proportion of residents within geographical proximity-based catchment areas who are receiving care from within the area and from outside. Bristol exports 31% of residents to other centres, the second highest proportion (Leicester exports 40%).

Congenital cardiac anomalies

4.3.8. The cardiac congenital anomaly rates were calculated using the National congenital anomaly register and 1996 live and still births. Although these show some variation between catchment areas, Bristol's rate of 1.34 per 1000 live and still births per year (95%CI 1.18-1.52) is not significantly different to the national rate of 1.24 (table 4.6).

***Referral* patterns and socio-economic deprivation**

4.3.9. For open operations in children under 1 year, in the Bristol catchment area, across deprivation quintiles, there was a gradient of movement out of the area, with 46% of patients in the least deprived areas going outside for treatment compared with only 15% living in the most deprived areas (p=0.003). A significant trend was also found in the Leicester catchment area and across the non-London areas as a whole (tables 4.7-10). There was no significant trend in UBHT for closed operations or for the older, 1 to 15, age group. There was a significant trend across the non-London catchment areas for both age groups and the closed procedures in the younger age group.

4.4. Discussion

4.4.1. As there are no reliable administrative catchment area definitions it is difficult to gauge activity levels. The results show how changing the definition of the catchment area can grossly affect estimates of patients flows and the activity rates for each centre. It is perhaps tautological to use the activity catchments when examining activity rates and flows, since the activity forms part of the definition as well as indicator. We therefore believe geographical proximity-based catchment areas are more useful in this analysis.

4.4.2. The main finding in using geographical proximity based catchment areas, is that for open procedures, the ratio of residents going out of the catchment area to those coming in to be operated on is high in Bristol. In the case of children aged under one year, there are no residents from England outside the catchment area coming in to UBHT to be operated on.

4.4.3. The centre activity for UBHT using geographical catchments is low but this figure is not surprising considering that Bristol is a net exporter of patients. A third of children under one year within the Bristol catchment area were being treated in other centres. One possible explanation is that UBHT was operating on the most severe cases, leaving the milder cases to go to other centres. If this were true, and making the ‘best case’ assumption that none of the Bristol cases treated in other centres would have died, then mortality at UBHT for open operations in children aged under 1 year (28%) would have been up to a third less (19%). In this ‘best case’ scenario however, mortality for open operations would still have been high compared to 11% elsewhere.

4.4.4. The catchment activity in the Bristol area is neither high nor low and gives no indication that the Bristol residents were either “over” or “under” operated. This finding is supported by the unremarkable cardiac congenital anomaly rates.

4.4.5. Residents in England, who are treated in Wales, were not included in this analysis. There are major problems in looking at Welsh data. HES does not included data on people treated in Welsh Hospitals. This is collected under a separate system and is called the Patient Episode Database for Wales or PEDW. In an unrelated study, we looked at the quality of these data and found that in some cases it was very poor, with hospitals missing as much as 36% of primary diagnoses. Welsh data quality up to 94/95 may be too poor for analysis (although there have been some updates to the 1994/95 data which have improved data quality). For this reason, we did not include PEDW data in this analysis. Welsh residents treated in England were also excluded. In total, 180 admissions for open/closed procedures with Welsh postcodes, treated at UBHT, were excluded.

4.4.6. Although there is a trend in Bristol for higher proportions of children under 1 year from affluent areas to be treated elsewhere for open operations, other centres also have this trend. We do not believe that residents in the Bristol area were that much different to the rest of the country in this respect.

4.4.7. In conclusion, there was a suggestion that activity rates were low in Bristol for open operations on residents within the catchment area, and this is supported by the numbers treated out of the area in other centres. However, this evidence is not compelling because of the difficulty in defining catchment areas.

5. Co-morbidity and casemix

5.1. Introduction

5.1.1. Differences in mortality rates between different centres may be explained, at least in part, by differences in severity of cases or casemix. HES provides no information on severity of cases, but there are several variables which may provide an indication of differences in casemix. Age is an important predictor of outcome. Mortality for open operations in children under 90 days for centres excluding UBHT is 16% compared to 5% in the 1-15 year age group. Primary diagnosis may be important, although no information on severity at diagnosis is available. Mention of specific diagnoses which may include multiple congenital anomalies such as Down’s syndrome may also affect mortality. Socio-economic deprivation may also affect mortality and can be estimated by the Carstairs deprivation index based on the postcode of residence in each admission.

5.1.2. This section looks at age, primary diagnosis, prevalence of Down’s syndrome and socio-economic deprivation amongst children operated on at the United Bristol Healthcare NHS Trust and elsewhere in England.

5.2. Methods

Age

5.2.1. The proportion of admissions by age for open and closed procedures was calculated.

Primary diagnoses

5.2.2. The primary diagnosis for each admission in the open or closed categories for UBHT and elsewhere in England was identified and the most frequent 3 digit ICD-9 and ICD-10 codes were identified.

Down’s syndrome

5.2.3. All diagnosis fields in each admission were checked for any mention of Down’s syndrome (ICD-9 758.0) and the percentage calculated for UBHT and for elsewhere in England.

Socio-economic deprivation

5.2.4. The Carstairs' deprivation score (derived from the 1991 census) was attached to each patient admission using the postcode to determine the enumeration district of residence.

5.3. Results

Age

5.3.1. The age distribution in UBHT was different to the rest of England, with a much smaller percentage of children (7%) in the under 90 days group compared with 22% for the rest of England, for open operations. For closed operations, the difference was less marked with 40% in the youngest age group in UBHT compared with 45% in the rest of England (table 5.1 and 5.2).

Primary diagnosis

5.3.2. There were apparent differences in primary diagnosis (table 5.3 and 5.4). UBHT had very few *ill-defined and unknown causes of morbidity and mortality* (ICD9 799 codes) with none in the open procedures and only one case in the closed category of procedures. This may account for some of the differences found in percentages for the other diagnoses. In UBHT and elsewhere, the most common primary diagnosis in the open class of procedures was "Bulbus cordis anomalies and anomalies of cardiac septal closure" (74% in UBHT, 63% elsewhere).

5.3.3. For closed procedures, the most common primary diagnosis was other congenital malformations (55% in UBHT, 44% elsewhere). There were also 41 cases of open wound of elbow, forearm and wrist, which may have been accidents or para suicides.

Down's syndrome

5.3.4. Within the open category of procedures, there were a larger proportion of children with a diagnosis of Down's syndrome in UBHT (10.3%, 95%CI 7.8-13.3) compared with the rest of England (7.0%, 95%CI 6.4-7.5%). In the closed category, the difference between UBHT (4.1%) and elsewhere (2.9%) was not statistically significant (table 5.5).

Socio-economic deprivation

5.3.5. For both open and closed procedures considered together, UBHT operated on a smaller proportion of patients living in the most deprived areas (Carstairs' Quintile 5) with 11% of admissions falling into this category compared with 22% elsewhere (Chi-square = 80, p<0.001) (table 5.6). UBHT also had many fewer admissions with missing postcodes, which fall into the 'unknown' category in the tables.

5.3.6. However table 5.7 shows that for open procedures performed in centres excluding UBHT, mortality does not appear to be related to deprivation. In the most deprived category for closed procedures, mortality does appear to be higher (6.2% in 5^{th} quintile compared to 3.9% in 4^{th} quintile, Chi-square = 5.29, p=0.021).

5.4. Discussion

5.4.1. The differences in age distribution between procedures carried out in at UBHT and elsewhere indicates that for children aged under 1 year, UBHT was operating on older patients (more than 90 days). As a greater proportion of operations were carried out on older children, mortality at age under 1 year, especially in open procedures, may be expected to be less than in other centres.

5.4.2. The differences in primary diagnosis are more difficult to interpret. There is an indication that primary diagnosis was better recorded in UBHT than the rest of England because the "bucket" code of *other ill-defined and unknown causes of morbidity and mortality* (ICD9 799) is only used once in UBHT in all admissions of open and closed procedures. In the rest of England, this code appears in 9% of admissions with open and 7% with closed procedures. Differences in other primary diagnosis may therefore be due to differences in coding accuracy rather than actual differences in diagnosis. The same may also be true of differences in the proportions of admissions with a mention of Down's syndrome, although these would not explain the large gap between UBHT mortality and elsewhere for neonatal open operations.

5.4.3. Deprivation is often associated with higher mortality, but for open procedures at least, there is little evidence for this. In any case, UBHT were operating on a smaller proportion of patients from the most deprived areas when compared with the rest of the country.

Acknowledgements

We would like to thank the following for their help in preparing this report. Wincen Lowe at Statistics Division at Department of Health, Mr Leslie Hamilton at the Freeman Hospital, Richard Brownnutt at IBM Global Services, Peter Benton at NHS Information Authority (Casemix Programme), Dr David Spiegelhalter, Medical Research Council Biostatistics Unit and Ian Maitland, Dr. Jon Wakefield and Dr. Tina Kold-Jensen at the Department of Epidemiology and Public Health at Imperial College School of Medicine, St. Mary's Campus.

This work was supported, in part, by an equipment grant from The Wellcome Trust (0455051/Z/95/Z). HES data: 'Source: Department of Health'. Census 1991 Population data (Small Area Statistics and Local Base Statistics), Crown Copyright. Digitised Boundary Data for England and Wales provided with the support of the ESRC.

The research on which this report is based was funded by the Bristol Royal Infirmary Inquiry. All views expressed in the report are the responsibility of the authors alone, and do not necessarily represent the views of the Bristol Royal Infirmary Inquiry.

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Figures and Tables

Table 2.1 Procedure groupings

Group	OPCS4 Procedure Code	Description	Primary procedure ranking	Open/ closed	Map to UKCSR †
G1	K04	Tetralogy of Fallot	9	Open	Yes
G2	K05	Interatrial TGA	5	Open	Yes
G3	K06	Other TGAs (- switch)	4	Open	Yes
G4	K07	Repair of TAPVD	3	Open	Yes
G5	K09 excluding K09.4	Repair of CAVSD (complete not partial)	6	Open	Yes
G6	K10, K20 and K09.4	Closure of secundum and sinus venosus ASDS	11	Open	Yes
G7	K11 (only on its own or with K10 or +/- L02; K11 is superior code to K10)	Closure of VSD	10	Open	Yes
G8	L01.1	Truncus arteriosus	1	Open	Yes
G9	K19.1, K19.2, K19.4 + L09	Fontan type operations	2	Open	Yes
G10	K26, K28, K31.2, K31.4, K37	Aortic, pulmonary valve and paravalve procedures	8	Open	Yes
G11	K25, K31.1, K34.1, K38	Mitral valve procedures	7	Open	Yes
G12	L05, L06, L07,L08	Closed shunts	12	Closed	No
G13	L23.1, 2 or 3 [- if K code with it, code as K not L]	Coarctation procedures	13	Closed	Yes

UKCSR † UK Cardiac surgical register

Table 2.2 Comparison of mortality between UBHT and the rest of England, Hospital Episode Statistics 1 April 1991 to 31 March 1995, age less than 90 days

	Total	UBHT					Elsewhere					
Procedure group	**n**	**n**	**Valid n* (%)**	**Died**	**%Died**	**95% CI**	**n**	**Valid n* (%)**	**Died**	**%Died**	**95% CI**	**Mortality Ratio**
1 Fallot †	40	0	0	0	0%		40	39 *(98)*	6	15%	6 - 31%	0.0
2 Interatrial TGA †	66	1	1 *(100)*	1	100%	2 - 100%	65	65 *(100)*	9	14%	7 - 25%	7.2
3 Other TGA †	591	13	10 *(77)*	9	90%	55 - 100%	578	531 *(92)*	54	10%	8 - 13%	8.9
4 TAPVD †	156	13	10 *(77)*	5	50%	19 - 81%	143	131 *(92)*	22	17%	11 - 24%	3.0
5 AVSD †	133	2	2 *(100)*	2	100%	16 - 100%	131	125 *(95)*	22	18%	11 - 25%	5.7
6 Closure of ASD †	70	2	2 *(100)*	0	0%	0 - 84%	68	64 *(94)*	8	13%	6 - 23%	0.0
7 Closure of VSD †	290	1	1 *(100)*	0	0%	0 - 98%	289	270 *(93)*	31	11%	8 - 16%	0.0
8 Truncus †	79	3	2 *(67)*	2	100%	16 - 100%	76	75 *(99)*	26	35%	24 - 47%	2.9
9 Fontan type †	38	0	0	0	0%		38	38 *(100)*	10	26%	13 - 43%	0.0
10 Aortic and pulmonary valves †	157	1	1 *(100)*	1	100%	2 - 100%	156	153 *(98)*	22	14%	9 - 21%	7.0
11 Mitral valves †	13	0	0	0	0%		13	11 *(85)*	6	55%	23 - 83%	0.0
12 Closed Shunts +	484	25	25 *(100)*	2	8%	1 - 26%	459	435 *(95)*	45	10%	8 - 14%	0.8
13 Simple Coarctation +	436	52	52 *(100)*	2	4%	0 - 13%	384	380 *(99)*	15	4%	2 - 6%	1.0
88 Open	1733	37	30 *(81)*	19	63%	44 - 80%	1696	1623 *(96)*	254	16%	14 - 18%	4.0
99 Closed	1530	99	96 *(97)*	5	5%	2 - 12%	1431	1415 *(99)*	72	5%	4 - 6%	1.0

*Admissions excluded if both length of stay less than 30 days and discharge destination unknown
† Open procedure, + Closed procedure

Table 2.3 Comparison of mortality between UBHT and the rest of England, admissions between 1st April 1991 to 31st March 1995, aged 90 days to 1 year

	Total	UBHT					Elsewhere					
Procedure group	**n**	**n**	**Valid n* (%)**	**Died**	**%Died**	**95% CI**	**n**	**Valid n* (%)**	**Died**	**%Died**	**95% CI**	**Mortality Ratio**
1 Fallot †	263	3	3 *(100)*	0	0%	0 - 70%	260	242 *(93)*	12	5%	3 - 9%	0.0
2 Interatrial TGA †	52	19	14 *(74)*	1	7%	0 - 34%	33	33 *(100)*	2	6%	1 - 20%	1.2
3 Other TGA †	50	5	3 *(60)*	1	33%	1 - 91%	45	42 *(93)*	6	14%	5 - 29%	2.3
4 TAPVD †	46	4	4 *(100)*	0	0%	0 - 60%	42	35 *(83)*	1	3%	0 - 15%	0.0
5 AVSD †	309	23	21 *(91)*	9	43%	22 - 66%	286	277 *(97)*	26	9%	6 - 13%	4.6
6 Closure of ASD †	99	9	8 *(89)*	5	63%	24 - 91%	90	85 *(94)*	3	4%	1 - 10%	17.7
7 Closure of VSD †	629	56	46 *(82)*	0	0%	0 - 8%	573	544 *(95)*	14	3%	1 - 4%	0.0
8 Truncus †	27	4	2 *(50)*	1	50%	1 - 99%	23	22 *(96)*	5	23%	8 - 45%	2.2
9 Fontan type †	87	4	4 *(100)*	2	50%	7 - 93%	83	80 *(96)*	10	13%	6 - 22%	4.0
10 Aortic and pulmonary valves †	109	3	3 *(100)*	1	33%	1 - 91%	106	102 *(96)*	3	3%	1 - 8%	11.3
11 Mitral valves †	46	3	3 *(100)*	2	67%	9 - 91%	43	41 *(95)*	6	15%	6 - 29%	4.6
12 Closed Shunts +	192	13	13 *(100)*	1	8%	0 - 36%	179	174 *(97)*	13	7%	4 - 12%	1.0
13 Simple Coarctation +	67	12	12 *(100)*	0	0%	0 - 26%	55	55 *(100)*	2	4%	0 - 13%	0.0
88 Open	1776	135	113 *(84)*	22	19%	13 - 28%	1641	1562 *(95)*	102	7%	5 - 8%	3.0
99 Closed	568	57	57 *(100)*	2	4%	0 - 12%	511	509 *(100)*	18	4%	2 - 6%	1.0

*Admissions excluded if both length of stay less than 30 days and discharge destination unknown
† Open procedure, + Closed procedure

Table 2.4 Comparison of mortality between UBHT and the rest of England, admissions between 1st April 1991 to 31st March 1995, aged 1 to 15 years

	Total	UBHT					Elsewhere					
Procedure group	n	n	Valid n* (%)	Died	%Died	95% CI	n	Valid n* (%)	Died	%Died	95% CI	Mortality Ratio
1 Fallot †	625	48	44 *(92)*	5	11%	4 - 25%	577	558 *(97)*	27	5%	3 - 7%	2.3
2 Interatrial TGA †	47	4	3 *(75)*	1	33%	1 - 91%	43	43 *(100)*	3	7%	1 - 19%	4.8
3 Other TGA †	61	9	6 *(67)*	1	17%	0 - 64%	52	47 *(90)*	3	6%	1 - 18%	2.6
4 TAPVD †	34	1	0 *(0)*	0	0%		33	32 *(97)*	1	3%	0 - 16%	0.0
5 AVSD †	391	11	11 *(100)*	1	9%	0 - 41%	380	367 *(97)*	14	4%	2 - 6%	2.4
6 Closure of ASD †	1177	81	80 *(99)*	0	0%	0 - 5%	1096	1064 *(97)*	3	0%	0 - 1%	0.0
7 Closure of VSD †	525	48	46 *(96)*	1	2%	0 - 12%	477	468 *(98)*	20	4%	3 - 7%	0.5
8 Truncus †	7	1	1 *(100)*	0	0%	0 - 98%	6	6 *(100)*	1	17%	0 - 64%	0.0
9 Fontan type †	572	38	34 *(89)*	3	9%	2 - 24%	534	525 *(98)*	51	10%	7 - 13%	0.9
10 Aortic and pulmonary valves †	725	47	46 *(98)*	3	7%	1 - 18%	678	663 *(98)*	18	3%	2 - 4%	2.4
11 Mitral valves †	216	20	20 *(100)*	1	5%	0 - 25%	196	187 *(95)*	13	7%	4 - 12%	0.7
12 Closed Shunts +	339	27	27 *(100)*	4	15%	4 - 34%	312	305 *(98)*	18	6%	4 - 9%	2.5
13 Simple Coarctation +	194	28	28 *(100)*	0	0%	0 - 12%	166	166 *(100)*	0	0%	0 - 2%	
88 Open	4741	333	314 *(94)*	21	7%	4 - 10%	4408	4293 *(97)*	195	5%	4 - 5%	1.5
99 Closed	1295	89	89 *(100)*	0	0%	0 - 4%	1206	1200 *(100)*	21	2%	1 - 3%	0.0

*Admissions excluded if both length of stay less than 30 days and discharge destination unknown

† Open procedure, + Closed procedure

Table 2.5 Percentage of admissions with complications mentioned in any diagnosis field in admissions with open procedures, 0-15 years, 1 April 1991 to 31 March 1995

	UBHT			Elsewhere		
Complications	**diagnoses out of 505 admissions**	**%**	**95% CI**	**diagnoses out of 7,745 admissions**	**%**	**95% CI**
Central nervous system (ICD 997.0)	8	1.6%	0.7 - 3.1%	28	0.4%	0.2 - 0.5%
Cardiac (ICD9 997.1)	56	11.1%	8.5 - 14.2%	336	4.3%	3.9 - 4.8%
Respiratory (ICD9 997.3)	49	9.7%	7.3 - 12.6%	241	3.1%	2.7 - 3.5%
Urinary (ICD9 997.5)	13	2.6%	1.4 - 4.4%	100	1.3%	1.1 - 1.6%

Table 2.6 Percentage of admissions with complications mentioned in any diagnosis field in admissions with closed procedures, 0-15 years, 1 April 1991 to 31 March 1995

	UBHT			Elsewhere		
Complications	**diagnoses out of 245 admissions**	**%**	**95% CI**	**diagnoses out of 3,148 admissions**	**%**	**95% CI**
Central nervous system (ICD 997.0)	2	0.8%	0.1 - 2.9%	10	0.3%	0.2 - 0.6%
Cardiac (ICD9 997.1)	11	4.5%	2.3 - 7.9%	49	1.6%	1.2 - 2.1%
Respiratory (ICD9 997.3)	15	6.1%	3.5 - 9.9%	54	1.7%	1.3 - 2.2%
Urinary (ICD9 997.5)	3	1.2%	0.3 - 3.5%	39	1.2%	0.9 - 1.7%

Table 2.7 Length of stay in weeks for admissions with open or closed procedures, 1st April 1991 to 31st March 1995

	Open				Closed			
Weeks	**UBHT**	**%**	**Elsewhere**	**%**	**UBHT**	**%**	**Elsewhere**	**%**
0	7	2%	1717	27%	30	14%	1026	50%
1	214	56%	2829	45%	123	59%	646	32%
2	91	24%	899	14%	27	13%	185	9%
3	36	9%	399	6%	13	6%	78	4%
4	14	4%	205	3%	4	2%	42	2%
5	8	2%	110	2%	1	0%	11	1%
6	5	1%	50	1%	2	1%	15	1%
7	2	1%	40	1%	2	1%	9	0%
8+	7	2%	104	2%	5	2%	29	1%
Total	384		6353		207		2041	

Discharge to normal or temporary residence only and excluding deaths

Note: 0 = 0-7 days, 1=8-14 days, etc.

Table 3.1 Excess mortality and ranking for UBHT relative to the other 11 centres in England by procedure group

Procedure Group	Other 11 centres[†]			UBHT										
	Valid n	Died	%	Valid n	Died	%	Predicted Deaths	Excess deaths	(95%interval)	Prob excess>0	# of centres	Rank	(95% interval)	Prob Worst
Age group under 90 days														
1: Fallot	39	6	15%	0	0	NA	NA	NA		NA	NA	NA		NA
2: Interatrial TGA	65	9	14%	1	1	100%	0.1	0.9	(0 - 1)	0.86	9	9	(4 - 9)	0.7
3: Other TGA	531	54	10%	10	9	90%	1.2	7.8	(5 - 9)	1	12	12	(11 - 12)	0.9
4: TAPVD	131	22	17%	10	5	50%	1.7	3.3	(0 - 5)	0.97	11	11	(7 - 11)	0.58
5: AVSD	125	22	18%	2	2	100%	0.4	1.6	(0 - 2)	0.94	12	11.5	(7 - 12)	0.53
6: Closue of ASD	64	8	13%	2	0	0%	0.3	-0.3	(-1 - 0)	0	10	3.5	(1 - 10)	0.17
7: Closure of VSD	267	31	12%	1	0	0%	0.1	-0.1	(-1 - 0)	0	12	1	(1 - 12)	0.35
8: Truncus	75	26	35%	2	2	100%	0.7	1.3	(0 - 2)	0.86	12	11.5	(4 - 12)	0.4
9: Fontan type	38	10	26%	0	0	NA	NA	NA		NA	NA	NA		NA
10: Aortic/pul val	149	22	15%	1	1	100%	0.2	0.8	(0 - 1)	0.84	12	12	(5 - 12)	0.75
11: Mitral valve	11	6	55%	0	0	NA	NA	NA		NA	NA	NA		NA
12: Closed shunts	430	45	10%	25	2	8%	2.6	-0.6	(-5 - 2)	0.33	12	6	(2 - 11)	0.02
13: Simple coarct	372	15	4%	52	2	4%	2.2	-0.2	(-4 - 2)	0.42	12	6	(1 - 11)	0.01
Groups 1-13 Total	2297	276	12%	106	24	23%	9.5	14.5	(7 - 22)	1				
Age group 90 days to under 1 year														
1: Fallot	242	12	5%	3	0	0%	0.2	-0.2	(-1 - 0)	0	12	2.5	(1 - 12)	0.25
2: Interatrial TGA	33	2	6%	14	1	7%	0.9	0.1	(-3 - 1)	0.5	11	9	(1 - 9)	0
3: Other TGA	42	6	14%	3	1	33%	0.4	0.6	(-1 - 1)	0.64	10	9.5	(2 - 10)	0.21
4: TAPVD	35	1	3%	4	0	0%	0.1	-0.1	(-1 - 0)	0	10	5	(1 - 10)	0.05
5: AVSD	277	26	9%	21	9	43%	2	7	(3 - 9)	1	12	12	(10 - 12)	0.8
6: Closue of ASD	85	3	4%	8	5	63%	0.3	4.7	(3 - 5)	1	11	11	(9 - 11)	0.7
7: Closure of VSD	544	14	3%	46	0	0%	1.3	-1.3	(-5 - 0)	0	12	2.5	(1 - 10)	0
8: Truncus	22	5	23%	2	1	50%	0.5	0.5	(-1 - 1)	0.61	12	9	(2 - 12)	0.06
9: Fontan type	80	10	13%	4	2	50%	0.5	1.5	(0 - 2)	0.9	10	10	(4 - 10)	0.38
10: Aortic/pul val	101	3	3%	3	1	33%	0.1	0.9	(0 - 1)	0.91	12	12	(5 - 12)	0.53
11: Mitral valve	40	6	15%	3	2	67%	0.5	1.5	(0 - 2)	0.92	11	11	(5 - 11)	0.39
12: Closed shunts	168	13	8%	13	1	8%	1.1	-0.1	(-3 - 1)	0.38	12	8	(1 - 11)	0.01
13: Simple coarct	54	2	4%	12	0	0%	0.5	-0.5	(-2 - 0)	0	11	5	(1 - 9)	0
Groups 1-13 Total	1723	103	6%	136	23	23%	8.4	14.6	(8 - 20)	1				
Age group 1 to 15 years														
1: Fallot	557	27	5%	44	5	11%	2.2	2.8	(-2 - 5)	0.89	12	11	(6 - 12)	0.13
2: Interatrial TGA	43	3	7%	3	1	33%	0.2	0.8	(0 - 1)	0.81	10	10	(3 - 10)	0.37
3: Other TGA	47	3	6%	6	1	17%	0.4	0.6	(-1 - 1)	0.68	8	6	(2 - 8)	0.09
4: TAPVD	32	1	3%	0	0	NA	NA	NA		NA	NA	NA		NA
5: AVSD	367	14	4%	11	1	9%	0.5	0.5	(-1 - 1)	0.64	12	9	(3 - 12)	0.13
6: Closue of ASD	1015	3	0%	80	0	0%	0.2	-0.2	(-2 - 0)	0	12	5	(1 - 11)	0.01
7: Closure of VSD	465	20	4%	46	1	2%	2	-1	(-5 - 1)	0.17	12	3	(1 - 11)	0.01
8: Truncus	6	1	17%	1	0	0%	0.2	-0.2	(-1 - 0)	0	6	3	(1 - 6)	0.13
9: Fontan type	525	51	10%	34	3	9%	3.5	-0.5	(-7 - 3)	0.41	12	7	(2 - 11)	0
10: Aortic/pul val	645	18	3%	46	3	7%	1.4	1.6	(-2 - 3)	0.83	12	11	(4 - 12)	0.18
11: Mitral valve	180	13	7%	20	1	5%	1.4	-0.4	(-4 - 1)	0.31	12	8	(1 - 11)	0.01
12: Closed shunts	292	18	6%	27	4	15%	1.8	2.2	(-2 - 4)	0.86	12	11	(4 - 12)	0.11
13: Simple coarct	159	0	0%	28	0	0%	0	0	(0 - 0)	0	12	6.5	(1 - 10)	0
Groups 1-13 Total	4333	172	4%	346	20	6%	13.8	6.2	(-4 - 15)	0.9				
All ages (0 to 15 years)														
1: Fallot	838	45	5%	47	5	11%	2.4	2.6	(-2 - 5)	0.88				
2: Interatrial TGA	141	14	10%	18	3	17%	1.2	1.8	(-1 - 3)	0.86				
3: Other TGA	620	63	10%	19	11	58%	2	9	(6 - 11)	1				
4: TAPVD	198	24	12%	14	5	36%	1.8	3.2	(0 - 5)	0.97				
5: AVSD	769	62	8%	34	12	35%	2.9	9.1	(5 - 12)	1				
6: Closue of ASD	1164	14	1%	90	5	6%	0.7	4.3	(2 - 5)	1				
7: Closure of VSD	1276	65	5%	93	1	1%	3.4	-2.4	(-7 - 1)	0.05				
8: Truncus	103	32	31%	5	3	60%	1.4	1.6	(-1 - 3)	0.86				
9: Fontan type	643	71	11%	38	5	13%	4	1	(-5 - 5)	0.64				
10: Aortic/pul val	895	43	5%	50	5	10%	1.7	3.3	(0 - 5)	0.96				
11: Mitral valve	231	25	11%	23	3	13%	1.9	1.1	(-3 - 3)	0.71				
12: Closed shunts	890	76	9%	65	7	11%	5.5	1.5	(-5 - 6)	0.68				
13: Simple coarct	585	17	3%	92	2	2%	2.7	-0.7	(-5 - 2)	0.32				
Groups 1-13 Total	8353	551	7%	588	67	11%	31.7	35.3	(21 - 48)	1				

NA indicates that no operations were carried out for that centre, procedure and age group

[†] Totals for 'Valid n' and 'Died' for the 11 specialist centres do not correspond exactly to the totals for 'elsewhere' in Section 2 which include a small number of admissions to other centres

Table 3.2 Excess mortality and ranking for UBHT relative to the other 11 centres in England for open and closed procedures

Procedure Group	Other 11 centres† Valid n	Died	%	UBHT Valid n	Died	%	Predicted Deaths	Excess deaths (95%interval)		Prob excess> 0	# of centres	Rank (95% interval)		Prob Worst
Age group under 90 days														
88: Open	1615	254	16%	30	19	63%	5.1	13.9	(8 - 18)	1.00	12	12	(12 - 12)	1.00
99: Closed	1323	61	5%	96	5	5%	4.6	0.4	(-7 - 5)	0.55	12	8	(2 - 12)	0.04
Open+Closed	2938	315	11%	126	24	19%	9.7	14.3	(6 - 21)	1.00				
Age group 90 days to under 1 year														
88: Open	1561	102	7%	113	22	19%	7.6	14.4	(7 - 20)	1.00	12	12	(11 - 12)	0.92
99: Closed	461	17	4%	57	2	4%	2.1	-0.1	(-4 - 2)	0.42	12	5	(1 - 11)	0.00
Open+Closed	2022	119	6%	170	24	14%	9.7	14.3	(6 - 21)	1.00				
Age group 1 to 15 years														
88: Open	4211	194	5%	314	21	7%	15	6	(-14 - 17)	0.80	12	11	(6 - 11)	0.00
99: Closed	893	15	2%	89	0	0%	1.7	-1.7	(-7 - 0)	0.00	12	3.5	(1 - 9)	0.01
Open+Closed	5104	209	4%	403	21	5%	16.7	4.3	(-16 - 16)	0.73				
All ages (0 to 15 years)														
88: Open	7387	550	7%	457	62	14%	27.7	34.3	(13 - 49)	0.99				
99: Closed	2677	93	3%	242	7	3%	8.4	-1.4	(-11 - 5)	0.35				
Open+Closed	10064	643	6%	669	69	10%	36.1	32.9	(9 - 49)	0.99				

† Totals for 'Valid n' and 'Died' for the 11 specialist centres do not correspond exactly to the totals for 'elsewhere' in Section 2 which include a small number of admissions to other centres

5.4.4.

Table 3.3 Excess deaths for each centre relative to the remaining centres by procedure and age group

Procedure Group	1	2	3	4	5	6	7	8	9	10	11	12	13	1-13	Open	Closed	Open & Closed
Centre	**Age Group under 90 days**																
UBHT	NA	0.9	7.8	3.3	1.6	-0.3	-0.1	1.3	NA	0.8	NA	-0.6	-0.2	14.5	13.9	0.4	14.3
2	-0.2	-1.0	-0.7	-0.6	0.6	1.9	-1.6	0.5	-0.3	0.7	NA	-3.3	1.9	-2.1	-4.1	1.4	-2.7
3	-0.4	-0.3	-6.8	-1.5	-5.1	-1.4	-1.6	-3.7	-0.3	-0.6	NA	-2.1	0.8	-23.0	-25.5	-1.5	-27
4	0.5	-0.2	0.1	0.0	0.8	1.1	0.5	0.6	NA	2.2	1.1	-1.3	0.0	5.4	4.6	-1.1	3.5
5	NA	NA	-5.1	1.3	3.0	NA	0.3	-1.4	0.8	-0.2	-0.6	0.8	-0.2	-1.3	1	0.9	1.9
6	0.8	1.4	1.4	-1.5	-0.5	-0.5	-0.4	-2.3	0.8	-4.0	-0.6	7.1	0.8	2.5	-5	7	2
7	-2.0	-0.5	-0.8	-1.7	0.9	NA	-1.6	0.9	-0.1	-0.8	NA	0.4	-0.7	-6.0	-7.5	-1.3	-8.8
8	-1.6	-0.9	-11.1	1.2	-3.2	-0.8	1.9	1.0	-0.6	1.1	0.5	-2.8	-0.9	-16.2	-17.1	0.4	-16.7
9	NA	NA	-2.6	0.7	0.8	-0.1	-0.8	0.9	NA	0.3	NA	1.0	-0.2	0.0	0.5	-0.6	-0.1
10	0.7	0.6	0.7	NA	0.8	0.0	1.1	-0.4	-0.3	-1.1	NA	3.5	0.5	6.1	-0.1	1.2	1.1
11	-0.8	NA	-19.3	-0.8	-6.4	0.8	-2.4	0.1	0.4	-2.5	-0.2	1.6	0.2	-29.3	-31.3	-2.9	-34.2
12	0.8	0.4	-2.4	-1.2	-1.0	-0.4	3.7	0.5	-0.3	1.0	NA	-3.8	-3.0	-5.7	-4.8	-7.8	-12.6
	Age group 90 days to under 1 year																
UBHT	-0.2	0.1	0.6	-0.1	7.0	4.7	-1.3	0.5	1.5	0.9	1.5	-0.1	-0.5	14.6	14.4	-0.1	14.3
2	-0.7	0.8	NA	0.0	2.1	-0.6	1.0	0.8	-0.2	0.8	-0.4	-1.0	-0.2	2.4	1.9	-0.7	1.2
3	-0.4	-0.4	1.0	-0.1	-0.3	-0.1	-1.6	-0.3	NA	-0.1	-0.6	-0.3	-0.2	-3.4	-3.6	0.0	-3.6
4	-0.2	NA	NA	-0.1	-0.9	-0.2	2.3	1.6	NA	-0.2	NA	-0.4	0.9	2.8	0.6	-1.4	-0.8
5	0.7	-0.2	-0.5	NA	-1.7	NA	1.3	0.8	-0.9	-0.2	-0.2	-0.2	NA	-1.1	-0.9	0.4	-0.5
6	1.3	-0.1	-0.2	-0.2	-3.6	-0.8	-1.7	-0.6	2.4	-1.1	0.0	-1.6	-0.2	-6.4	-7.0	-0.1	-7.1
7	-0.2	-0.1	-0.9	-0.1	-2.1	-0.6	0.0	-0.3	0.4	-0.4	-0.8	0.8	-0.1	-4.4	-4.0	-0.7	-4.7
8	0.1	0.7	-1.2	1.0	-2.0	1.1	-1.3	-0.3	-0.1	-0.4	2.1	1.1	0.8	1.6	-0.7	0.5	-0.2
9	-0.5	-0.2	0.6	-0.1	0.6	-0.2	-1.0	-1.2	-0.3	-0.2	0.7	-0.8	0.0	-2.6	-1.0	-1.0	-2.0
10	1.2	-0.2	-0.3	NA	0.3	-0.9	1.0	-0.3	0.6	-0.3	-0.4	1.4	-0.1	2.0	2.6	1.2	3.8
11	-1.0	-0.1	0.9	-0.3	-2.7	-1.2	-1.6	-0.7	-4.7	0.2	-0.2	1.6	-0.1	-9.9	-6.3	0.5	-5.8
12	-1.0	-0.4	-0.2	-0.1	0.1	-1.4	0.8	-0.6	-0.7	0.6	-2.1	-2.1	-0.4	-7.5	-6.6	0.9	-5.7
	Age group 1 to 15 years																
UBHT	2.8	0.8	0.6	NA	0.5	-0.2	-1.0	-0.2	-0.5	1.6	-0.4	2.2	0.0	6.2	6.0	-1.7	4.3
2	-0.2	-0.2	NA	-0.1	0.2	-0.2	-1.0	NA	-1.4	-0.1	-0.2	-0.8	0.0	-4.0	-6.3	-1.3	-7.6
3	-1.5	-0.6	0.9	-0.1	2.1	-0.4	0.1	NA	-1.2	0.9	0.0	1.1	0.0	1.3	-0.7	-2.6	-3.3
4	-0.6	NA	NA	0.0	0.7	0.9	-1.3	NA	0.7	-0.7	-0.3	0.0	0.0	-0.6	-2.7	0.8	-1.9
5	-3.0	NA	-0.4	0.0	-2.0	0.0	0.2	NA	-3.7	0.0	1.4	0.3	0.0	-7.2	-3.9	-0.2	-4.1
6	-0.9	-0.4	-0.5	-0.1	-0.7	0.5	0.2	-0.2	-2.8	-3.0	-2.3	-2.2	0.0	-12.4	-11.2	-1.7	-12.9
7	-0.8	-0.3	0.7	-0.2	0.2	-0.2	-0.1	-0.2	-2.6	0.2	-0.5	-0.8	0.0	-4.6	-7.1	-0.4	-7.5
8	-1.5	0.7	-0.2	-0.2	-1.9	-0.6	-1.6	-0.2	1.0	-1.0	4.6	0.1	0.0	-0.8	-0.4	-3.0	-3.4
9	0.2	-0.5	NA	1.0	-1.7	-0.1	0.8	-0.2	2.6	-0.8	-0.8	0.4	0.0	0.9	2.5	1.8	4.3
10	7.0	-0.6	NA	NA	-0.3	-0.2	1.8	1.0	6.1	2.8	-0.9	2.9	0.0	19.6	22.4	4.5	26.9
11	-0.6	-0.5	-1.3	-0.1	-2.2	0.7	0.6	NA	-4.6	-2.4	0.6	-1.8	0.0	-11.6	-13.7	1.5	-12.2
12	-3.1	1.5	-0.5	-0.1	1.5	-0.4	0.3	NA	2.9	0.2	-1.4	-4.5	0.0	-3.6	1.9	-2.4	-0.5
	All Ages (0 to 15 years)																
UBHT	2.6	1.8	9.0	3.2	9.1	4.2	-2.4	1.6	1.0	3.3	1.1	1.5	-0.7	35.3	34.3	-1.4	32.9
2	-1.1	-0.4	-0.7	-0.7	2.9	1.1	-1.6	1.3	-1.9	1.4	-0.6	-5.1	1.7	-3.7	-8.5	-0.6	-9.1
3	-2.3	-1.3	-4.9	-1.7	-3.3	-1.9	-3.1	-4.0	-1.5	0.2	-0.6	-1.3	0.6	-25.1	-29.8	-4.1	-33.9
4	-0.3	-0.2	0.1	-0.1	0.6	1.8	1.5	2.2	0.7	1.3	0.8	-1.7	0.9	7.6	2.5	-1.7	0.8
5	-2.3	-0.2	-6.0	1.3	-0.7	0.0	1.8	-0.6	-3.8	-0.4	0.6	0.9	-0.2	-9.6	-3.8	1.1	-2.7
6	1.2	0.9	0.7	-1.8	-4.8	-0.8	-1.9	-3.1	0.4	-8.1	-2.9	3.3	0.6	-16.3	-23.2	5.2	-18.0
7	-3.0	-0.9	-1.0	-2.0	-1.0	-0.8	-1.7	0.4	-2.3	-1.0	-1.3	0.4	-0.8	-15.0	-18.6	-2.4	-21.0
8	-3.0	0.5	-12.5	2.0	-7.1	-0.3	-1.0	0.5	0.3	-0.3	7.2	-1.6	-0.1	-15.4	-18.2	-2.1	-20.3
9	-0.3	-0.7	-2.0	1.6	-0.3	-0.4	-1.0	-0.5	2.3	-0.7	-0.1	0.6	-0.2	-1.7	2.0	0.2	2.2
10	8.9	-0.2	0.4	0.0	0.8	-1.1	3.9	0.3	6.4	1.4	-1.3	7.8	0.4	27.7	24.9	6.9	31.8
11	-2.4	-0.6	-19.7	-1.2	-11.3	0.3	-3.4	-0.6	-8.9	-4.7	0.2	1.4	0.1	-50.8	-51.3	-0.9	-52.2
12	-3.3	1.5	-3.1	-1.4	0.6	-2.2	4.8	-0.1	1.9	1.8	-3.5	-10.4	-3.4	-16.8	-9.5	-9.3	-18.8

[grey box] Indicates that we are at least 95% certain that the number of excess deaths > 0

Table 4.1 Geographical catchment area[†]: children aged under 1 year. Admissions (excluding Welsh residents) by specialist centre between 1st April 1991 and 31st March 1995

Procedure class – Open				Activity				
	Missing Postcode	**Admissions**	**Pop'n ***	**Centre Rate/1000 per year**	**Catchment Rate/1000 per year**	**Out**	**In**	**Flow Ratio Out/In**
Bristol	1	141	49217	0.72	1.09	73	0	-
Birmingham	50	415	70255	1.48	1.51	9	119	0.1
Leeds	25	281	76925	0.91	1.11	60	17	3.5
Leicester	4	174	51710	0.84	1.31	96	11	8.7
Liverpool	4	317	80316	0.99	1.24	81	35	2.3
Newcastle	6	185	36462	1.27	1.28	2	4	0.5
Oxford	1	29	7667	0.95	0.95	0	93	0.0
Southampton	19	167	28800	1.45	1.56	13	52	0.3
London	351	836	235539	0.89	0.97	76	71	1.1
Procedure class – Closed								
Bristol	3	123	49217	0.62	0.83	41	5	8.2
Birmingham	12	235	70255	0.84	0.88	12	26	0.5
Leeds	21	187	76925	0.61	0.72	34	16	2.1
Leicester	2	122	51710	0.59	0.95	75	13	5.8
Liverpool	4	200	80316	0.62	0.85	73	12	6.1
Newcastle	3	109	36462	0.75	0.75	1	4	0.3
Oxford	4	33	7667	1.08	1.08	0	83	0.0
Southampton	7	52	28800	0.45	0.54	10	22	0.5
London	135	448	235539	0.48	0.57	93	22	4.2

[†] Geographical Information Software was used to determine the distance from the population centroid of each HA (1996 boundaries) to each specialist centre. Each HA was then allocated to the nearest specialist centre catchment area.
* Live births

Table 4.2 Empirical catchment area[†]: children aged under 1 year. Admissions (excluding Welsh residents) by specialist centre between 1st April 1991 and 31st March 1995

Procedure class – Open				Activity				
	Missing Postcode	Admissions	Pop'n *	Centre Rate/1000 per year	Catchment Rate/1000 per year	Out	In	Flow Ratio Out/In
Bristol	1	121	34425	0.88	1.18	41	20	2.1
Birmingham	50	415	70255	1.48	1.51	9	119	0.1
Leeds	25	279	70577	0.99	1.07	23	19	1.2
Leicester	4	166	38917	1.07	1.34	42	19	2.2
Liverpool	4	343	86663	0.99	1.26	94	9	10.4
Newcastle	6	185	36462	1.27	1.28	2	4	0.5
Oxford	1	115	42687	0.67	1.11	74	7	10.6
Southampton	19	183	35881	1.28	1.43	22	36	0.6
London	351	818	221024	0.93	0.95	23	89	0.3
Procedure class – Closed								
Bristol	3	106	34425	0.77	0.89	17	22	0.8
Birmingham	12	235	70255	0.84	0.88	12	26	0.5
Leeds	21	186	70577	0.66	0.74	22	17	1.3
Leicester	2	114	38917	0.73	1.03	47	21	2.2
Liverpool	4	208	86663	0.60	0.83	78	4	19.5
Newcastle	3	109	36462	0.75	0.75	1	4	0.3
Oxford	4	110	42687	0.64	0.81	28	6	4.7
Southampton	7	59	35881	0.41	0.56	21	15	1.4
London	135	448	221024	0.51	0.56	47	22	2.1

[†] The number of admissions from each HA (1996 boundaries) to each specialist centre was calculated for the 13 procedure groups combined and from the open or closed classes. Each health authority was then allocated to a specialist centre catchment area, according to the centre which undertook the largest proportion of operations of residents within that HA.
* Live births

Table 4.3 Geographical catchment area†: children aged 1 to 15 years. Admissions (excluding Welsh residents) by specialist centre between 1st April 1991 and 31st March 1995

Procedure class – Open	Missing Postcode	Admissions	Pop'n *	Activity Centre Rate/1000 per year	Catchment Rate/1000 per year	Out	In	Flow Ratio Out/In
Bristol	1	220	755187	0.07	0.10	90	9	10.0
Birmingham	32	427	1053011	0.10	0.11	22	65	0.3
Leeds	32	350	1150722	0.08	0.10	102	24	4.3
Leicester	3	201	781372	0.06	0.11	133	12	11.1
Liverpool	10	610	1230960	0.12	0.14	88	44	2.0
Newcastle	11	203	573080	0.09	0.09	10	15	0.7
Oxford	2	58	112881	0.13	0.16	12	112	0.1
Southampton	16	166	438704	0.09	0.11	19	64	0.3
London	491	1118	3273293	0.09	0.09	104	156	0.7
Procedure class – Closed								
Bristol	1	65	755187	0.02	0.04	45	1	45.0
Birmingham	1	76	1053011	0.02	0.03	30	7	4.3
Leeds	7	103	1150722	0.02	0.03	55	5	11.0
Leicester	2	57	781372	0.02	0.04	55	2	27.5
Liverpool	2	61	1230960	0.01	0.03	92	7	13.1
Newcastle	1	59	573080	0.03	0.03	18	6	3.0
Oxford	0	18	112881	0.04	0.04	0	48	0.0
Southampton	9	42	438704	0.02	0.03	7	15	0.5
London	79	248	3273293	0.02	0.03	119	24	5.0

† Geographical Information Software was used to determine the distance from the population centroid of each HA (1996 boundaries) to each specialist centre. Each HA was then allocated to the nearest specialist centre catchment area.
*1991 census

Table 4.4 Empirical catchment area† : children aged 1 to 15 years. Admissions (excluding Welsh residents) by specialist centre between 1st April 1991 and 31st March 1995

Procedure class – Open	Missing Postcode	Admissions	Pop'n *	Activity: Centre Rate/1000 per year	Catchment Rate/1000 per year	Out	In	Flow Ratio Out/In
Bristol	1	188	530950	0.09	0.10	34	41	0.8
Birmingham	32	427	1053011	0.10	0.11	22	65	0.3
Leeds	32	349	1057391	0.08	0.10	61	25	2.4
Leicester	3	198	588092	0.08	0.11	63	15	4.2
Liverpool	10	639	1324291	0.12	0.14	101	15	6.7
Newcastle	11	203	573080	0.09	0.09	10	15	0.7
Oxford	2	159	637230	0.06	0.11	112	11	10.2
Southampton	16	192	549250	0.09	0.11	44	38	1.2
London	491	1096	3055915	0.09	0.09	35	178	0.2
Procedure class – Closed								
Bristol	1	57	530950	0.03	0.04	25	9	2.8
Birmingham	1	76	1053011	0.02	0.03	30	7	4.3
Leeds	7	103	1057391	0.02	0.04	46	5	9.2
Leicester	2	57	588092	0.02	0.04	30	2	15.0
Liverpool	2	65	1324291	0.01	0.03	97	3	32.3
Newcastle	1	59	573080	0.03	0.03	18	6	3.0
Oxford	0	63	637230	0.02	0.04	29	3	9.7
Southampton	9	49	549250	0.02	0.03	15	8	1.9
London	79	246	3055915	0.02	0.03	85	26	3.3

† The number of admissions from each HA (1996 boundaries) to each specialist centre was calculated for the 13 procedure groups combined and from the open or closed classes. Each health authority was then allocated to a specialist centre catchment area, according to the centre which undertook the largest proportion of operations of residents within that HA.
* 1991 census

Table 4.5 Residents within Bristol geographical proximity-based catchment area† by centre of treatment for all operations

Centre	%
UBHT	69%
Southampton	16%
Radcliffe Infirmary, Oxford	5%
London hospitals	4%
Birmingham Children's Hospital	3%
Other than 12 major centres	3%

† Geographical Information Software was used to determine the distance from the population centroid of each HA (1996 boundaries) to each specialist centre. Each HA was then allocated to the nearest specialist centre catchment area.

Table 4.6 Congenital cardiac anomaly notification rate - by geographic proximity-based catchment areas† - 1991-1994

	n	Live and still births based on 1996 data	Annual Rate per 1000	95% CI
Bristol	258	48049	1.34	1.18 - 1.52
Birmingham	348	67920	1.28	1.15 - 1.42
Leeds	487	72901	1.67	1.53 - 1.82
Leicester	294	50227	1.46	1.30 - 1.64
Liverpool	370	75887	1.22	1.10 - 1.35
Newcastle	163	33868	1.20	1.03 - 1.40
Oxford	12	7327	0.41	0.21 - 0.71
Southampton	132	28008	1.18	0.99 - 1.40
London	1094	233342	1.17	1.10 - 1.24

† Geographical Information Software was used to determine the distance from the population centroid of each HA (1996 boundaries) to each specialist centre. Each HA was then allocated to the nearest specialist centre catchment area.

Table 4.7 Percentage of admissions exported as a proportion of all admissions in geographical catchment area† residents by Carstairs quintiles - age under 1 year - o*pen* between 1st April 1991 to 31st March 1995

	Least Deprived								Most Deprived		
	Quintile 1		Quintile 2		Quintile 3		Quintile 4		Quintile 5		Chi squared
	Exported		Exported		Exported		Exported		Exported		for trend
Geographical Catchment Areas	n	%	n	%	n	%	n	%	n	%	p
Bristol	22	46%	25	39%	17	31%	6	21%	3	15%	0.003
Birmingham	2	3%	2	3%	2	3%	2	2%	1	1%	0.15
Leeds	1	3%	8	18%	19	24%	10	14%	21	18%	0.40
Leicester	18	42%	30	49%	18	30%	16	30%	13	26%	0.012
Liverpool	6	11%	15	22%	21	28%	13	19%	26	20%	0.59
Newcastle	1	6%	0	0%	0	0%	0	0%	1	1%	0.39
Oxford	0	0%	0	0%	0	0%	0	0%	0	0%	.
Southampton	3	7%	4	7%	2	5%	3	12%	1	6%	0.91
Total for non-London areas	53	17%	84	22%	79	19%	50	13%	66	12%	<0.001

† Geographical Information Software was used to determine the distance from the population centroid of each HA (1996 boundaries) to each specialist centre. Each HA was then allocated to the nearest specialist centre catchment area.

Table 4.8 Percentage of admissions exported as a proportion of all admissions in geographical catchment area † residents by Carstairs quintiles - age 1 to 15 year - *open* between 1st April 1991 to 31st March 1995

	Least Deprived								Most Deprived		
	Quintile 1		Quintile 2		Quintile 3		Quintile 4		Quintile 5		Chi squared
	Exported		Exported		Exported		Exported		Exported		for trend
Geographical Catchment Areas	n	%	n	%	n	%	n	%	n	%	p
Bristol	13	19%	30	41%	22	26%	20	33%	5	22%	0.71
Birmingham	9	16%	4	6%	5	6%	2	2%	2	1%	<0.001
Leeds	17	31%	18	23%	16	22%	19	22%	31	19%	0.12
Leicester	31	57%	27	41%	27	39%	21	34%	27	33%	0.006
Liverpool	15	15%	13	11%	13	13%	15	10%	32	14%	0.95
Newcastle	2	9%	0	0%	0	0%	3	8%	5	5%	0.64
Oxford	1	9%	6	20%	5	42%	0	0%	0	0%	0.49
Southampton	9	18%	2	5%	6	14%	1	4%	1	5%	0.09
Total for non-London areas	97	23%	100	20%	94	19%	81	15%	103	14%	<0.001

† Geographical Information Software was used to determine the distance from the population centroid of each HA (1996 boundaries) to each specialist centre. Each HA was then allocated to the nearest specialist centre catchment area.

Table 4.9 Percentage of admissions exported as a proportion of all admissions in geographical catchment area † residents by Carstairs quintiles - age under 1 year - *closed* between 1st April 1991 to 31st March 1995

	Least Deprived								Most Deprived		
	Quintile 1		Quintile 2		Quintile 3		Quintile 4		Quintile 5		Chi squared
	Exported		Exported		Exported		Exported		Exported		for trend
Geographical Catchment Areas	n	%	n	%	n	%	n	%	n	%	p
Bristol	7	27%	15	29%	9	20%	6	19%	4	40%	0.78
Birmingham	1	3%	4	12%	3	9%	1	2%	2	2%	0.09
Leeds	7	28%	4	17%	5	10%	6	14%	11	14%	0.22
Leicester	12	50%	17	34%	16	42%	12	27%	18	44%	0.69
Liverpool	6	21%	10	27%	12	28%	19	33%	26	25%	0.82
Newcastle	0	0%	0	0%	0	0%	0	0%	1	2%	0.33
Oxford	0	0%	0	0%	0	0%	0	0%	0	0%	.
Southampton	7	30%	1	13%	1	6%	1	11%	0	0%	0.03
Total for non-London areas	40	24%	51	22%	46	18%	45	17%	62	16%	0.014

† Geographical Information Software was used to determine the distance from the population centroid of each HA (1996 boundaries) to each specialist centre. Each HA was then allocated to the nearest specialist centre catchment area.

Table 4.10 Percentage of admissions exported as a proportion of all admissions in geographical catchment area † residents by Carstairs quintiles - age 1 to 15 year - *closed* between 1st April 1991 to 31st March 1995

	Least Deprived								Most Deprived		
	Quintile 1		Quintile 2		Quintile 3		Quintile 4		Quintile 5		Chi squared
	Exported		Exported		Exported		Exported		Exported		for trend
Geographical Catchment Areas	n	%	N	%	n	%	n	%	n	%	p
Bristol	*8*	40%	*18*	47%	*9*	39%	*6*	27%	*4*	57%	0.64
Birmingham	*2*	12%	*7*	47%	*5*	23%	*6*	32%	*10*	30%	0.47
Leeds	*6*	38%	*12*	38%	*7*	26%	*14*	52%	*16*	29%	0.63
Leicester	*10*	53%	*12*	52%	*11*	48%	*10*	45%	*12*	48%	0.64
Liverpool	*14*	70%	*13*	50%	*15*	75%	*23*	62%	*27*	54%	0.44
Newcastle	*2*	33%	*2*	20%	*4*	44%	*4*	27%	*6*	16%	0.26
Oxford	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	.
Southampton	*4*	31%	*0*	0%	*3*	21%	*0*	0%	*0*	0%	0.07
Total for non-London areas	*46*	40%	*64*	41%	*54*	38%	*63*	41%	*75*	35%	0.34

† Geographical Information Software was used to determine the distance from the population centroid of each HA (1996 boundaries) to each specialist centre. Each HA was then allocated to the nearest specialist centre catchment area.

Table 5.1 Number and percentage of cases in each age group for open procedures between 1st April 1991 to 31st March 1995

	UBHT		Elsewhere	
Age	**n**	**%**	**n**	**%**
under 90 days	37	7%	1,696	22%
90 days – 1 year	135	27%	1,641	21%
1 - 15 years	333	66%	4,408	57%
Total	505		7,745	

Chi squared $p<0.001$

Table 5.2 Number and percentage of cases in each age group for closed procedures between 1st April 1991 to 31st March 1995

	UBHT		Elsewhere	
Age	**n**	**%**	**n**	**%**
under 90 days	99	40%	1,431	45%
90 days - 1 year	57	23%	511	16%
1 - 15 years	89	36%	1,206	38%
Total	245		3,148	

Chi squared $p<0.02$

Table 5.3 Most common primary diagnosis for open procedures between 1st April 1991 to 31st March 1995

Description	Diag	UBHT n	UBHT %	Elsewhere n	Elsewhere %
Bulbus cordis anomalies and anomalies of cardiac septal closure	745	374	74%	4871	63%
Other congenital anomalies of heart	746	56	11%	992	13%
Other congenital anomalies of circulatory system	747	56	11%	724	9%
Other ill-defined and unknown causes of morbidity	799	0	0%	727	9%
Other diseases of endocardium	424	1	0%	71	1%
Cardiomyopathy	425	0	0%	56	1%
Chromosomal anomalies	758	0	0%	46	1%
Complications peculiar to certain specified procedures	996	5	1%	30	0%
Congenital malformations of cardiac septum	Q21	1	0%	22	0%
Other and unspecified congenital anomalies	759	4	1%	13	0%
	Other	8	2%	193	2%
	Total	505		7745	

Table 5.4 Most common primary diagnosis for closed procedures between 1st April 1991 to 31st March 1995

Description	Diag	UBHT *n*	UBHT %	Elsewhere *n*	Elsewhere %
Other congenital anomalies of circulatory system	747	134	55%	1385	44%
Bulbus cordis anomalies and anomalies of cardiac septal closure	745	45	18%	588	19%
Other congenital anomalies of heart	746	27	11%	300	10%
Other ill-defined and unknown causes of morbidity	799	1	0%	218	7%
Other diseases of pericardium	423	1	0%	66	2%
Disorders relating to short gestation and unspecified low birth weight	765	6	2%	52	2%
Conduction disorders	426	2	1%	43	1%
Complications peculiar to certain specified procedures	996	1	0%	41	1%
Open wound of elbow - forearm and wrist	881	3	1%	38	1%
Fitting of Cardiac pacemaker	V53	0	0%	27	1%
	Other	25	10%	390	12%
	Total	245		3148	

Table 5.5 Number and percentage of admissions with Down's syndrome mentioned in any diagnosis field between 1st April 1991 to 31st March 1995

	UBHT			Elsewhere			
	cases	**%**	**95% CI**	**cases**	**%**	**95% CI**	
Open	52	10.3%	7.8 - 13.3%	539	7.0%	6.4%	7.5%
Closed	10	4.1%	2.0 - 7.4%	91	2.9%	2.3%	3.5%

Table 5.6 Percentage of open/closed procedures by Carstairs deprivation quintile - 1st April 1991 to 31st March 1995

	UBHT		Elsewhere	
Carstairs Quintile	**n**	**%**	**n**	**%**
1 – Least Deprived	130	17%	1625	15%
2	174	23%	1783	16%
3	197	26%	1833	17%
4	157	21%	1891	17%
5 – Most Deprived	85	11%	2391	22%
Unknown	7	1%	1370	13%

Excluding unknown, Chi-squared = 80.39, p<0.001

Table 5.7 Mortality for open procedures by Carstairs deprivation quintile for all centres combined (excluding UBHT) - 1st April 1991 to 31st March 1995

Carstairs quintile	n	Died	%
1 – Least Deprived	1161	77	6.6%
2	1274	101	7.9%
3	1281	87	6.8%
4	1327	100	7.5%
5 – Most Deprived	1634	120	7.3%
Unknown	1068	110	10.3%

Excluding unknown, Chi-squared test for trend = 0.168, p<0.682

Table 5.8 Mortality for closed procedures by Carstairs deprivation quintile for all centres combined (excluding UBHT) - 1st April 1991 to 31st March 1995

Carstairs quintile	n	Died	%
1 – Least Deprived	464	17	3.7%
2	509	20	3.9%
3	552	15	2.7%
4	564	23	4.1%
5 – Most Deprived	757	47	6.2%
Unknown	302	20	6.6%

Excluding unknown, Chi-squared test for trend = 5.289, p<0.021

Figure 2.1 Selection procedure from national HES data set

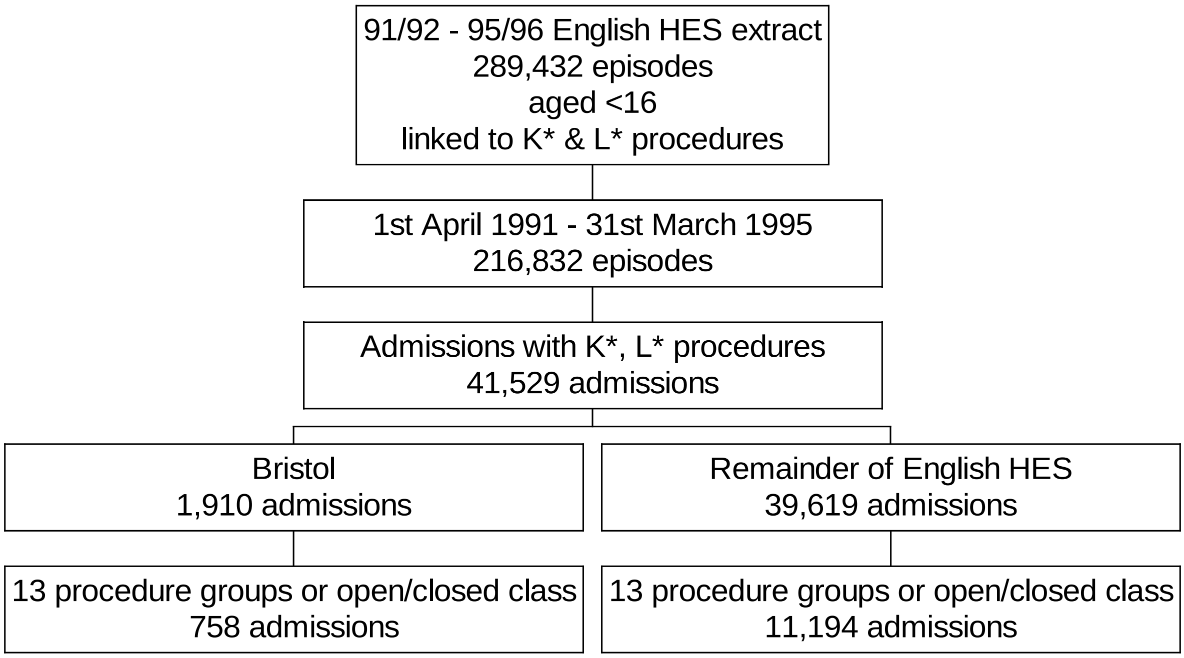


Figure 2.2 Comparison of mortality rates between UBHT and rest of the country - HES 1 April 1991 to 31 March 1995 - aged under 90 days

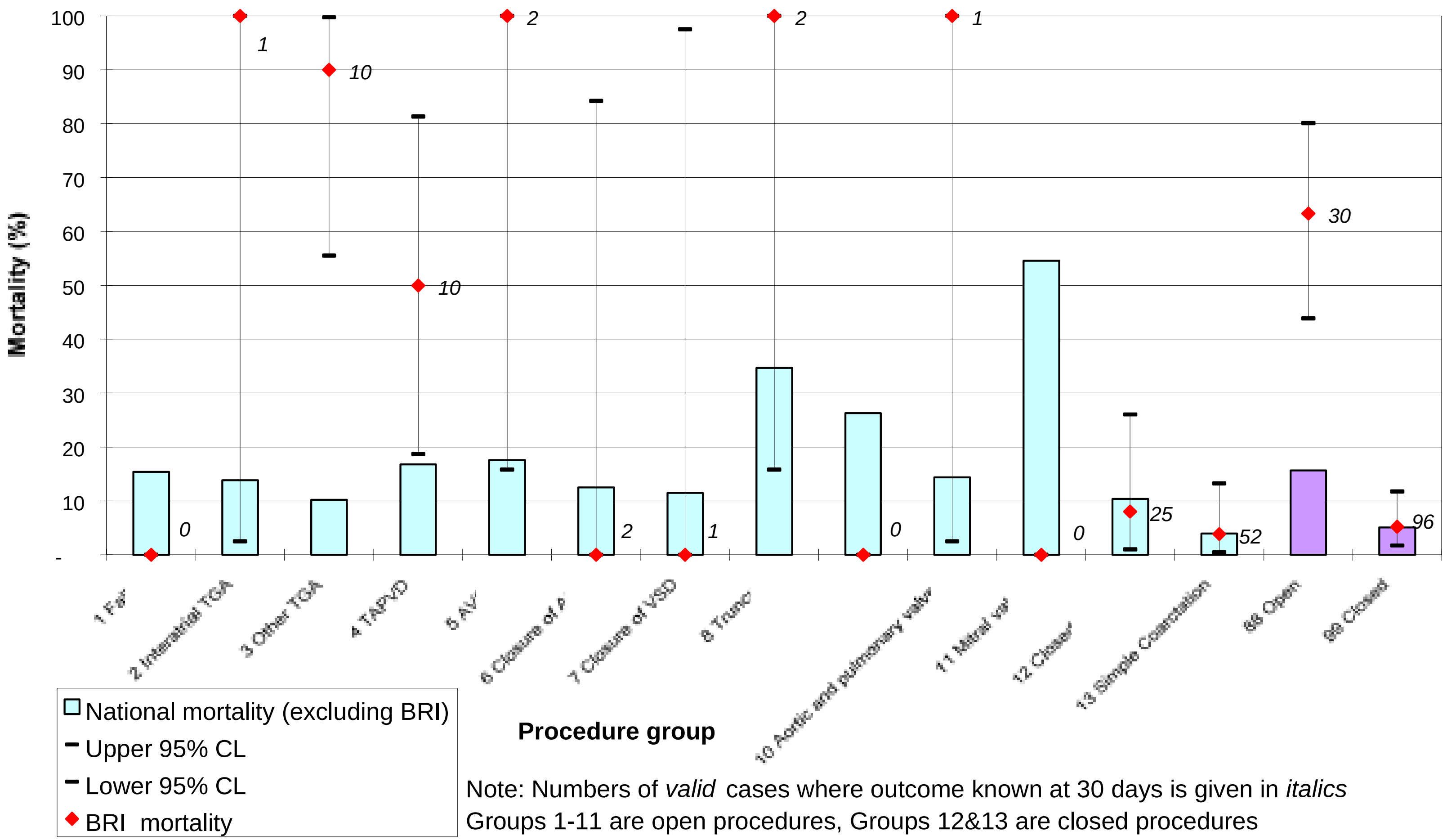
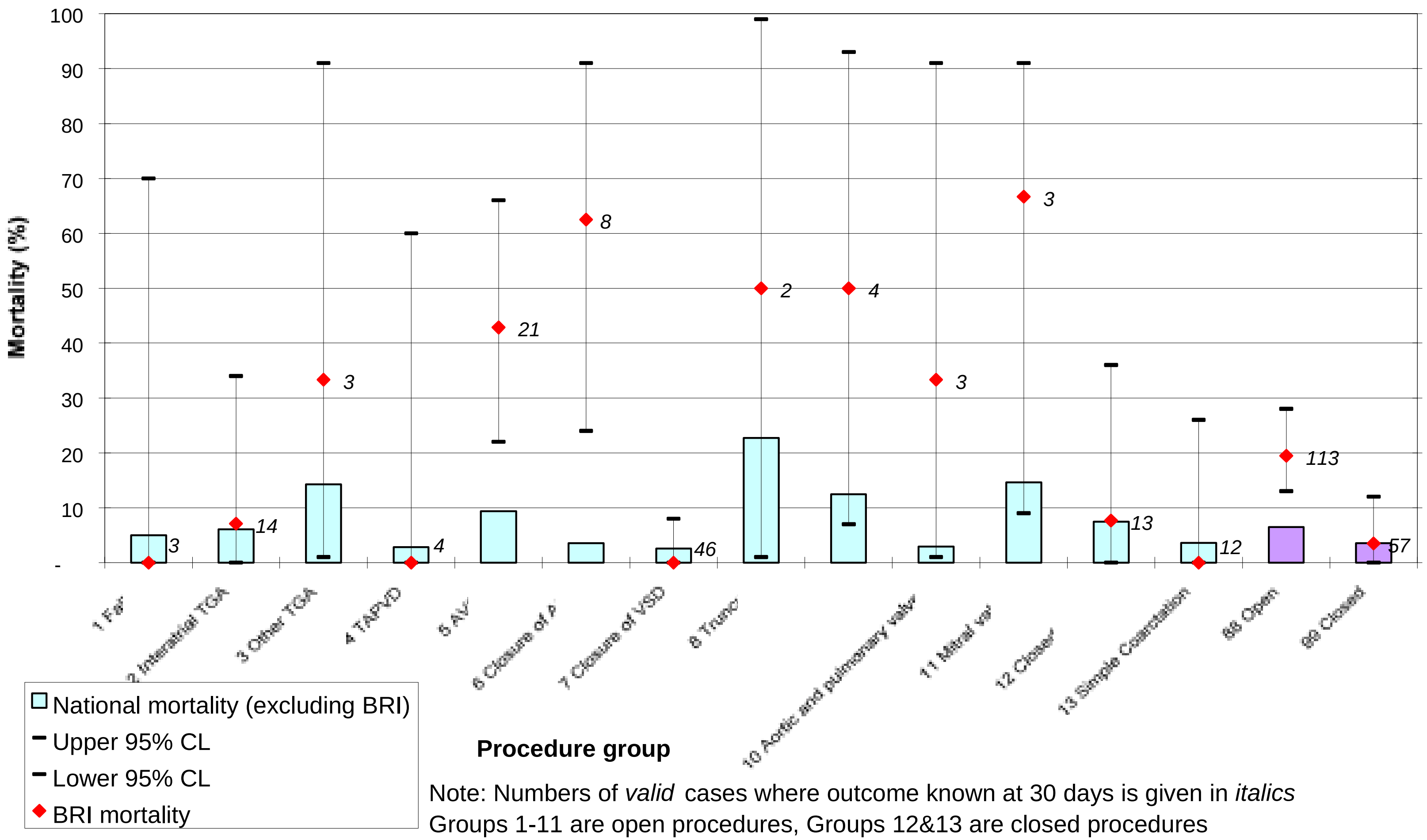
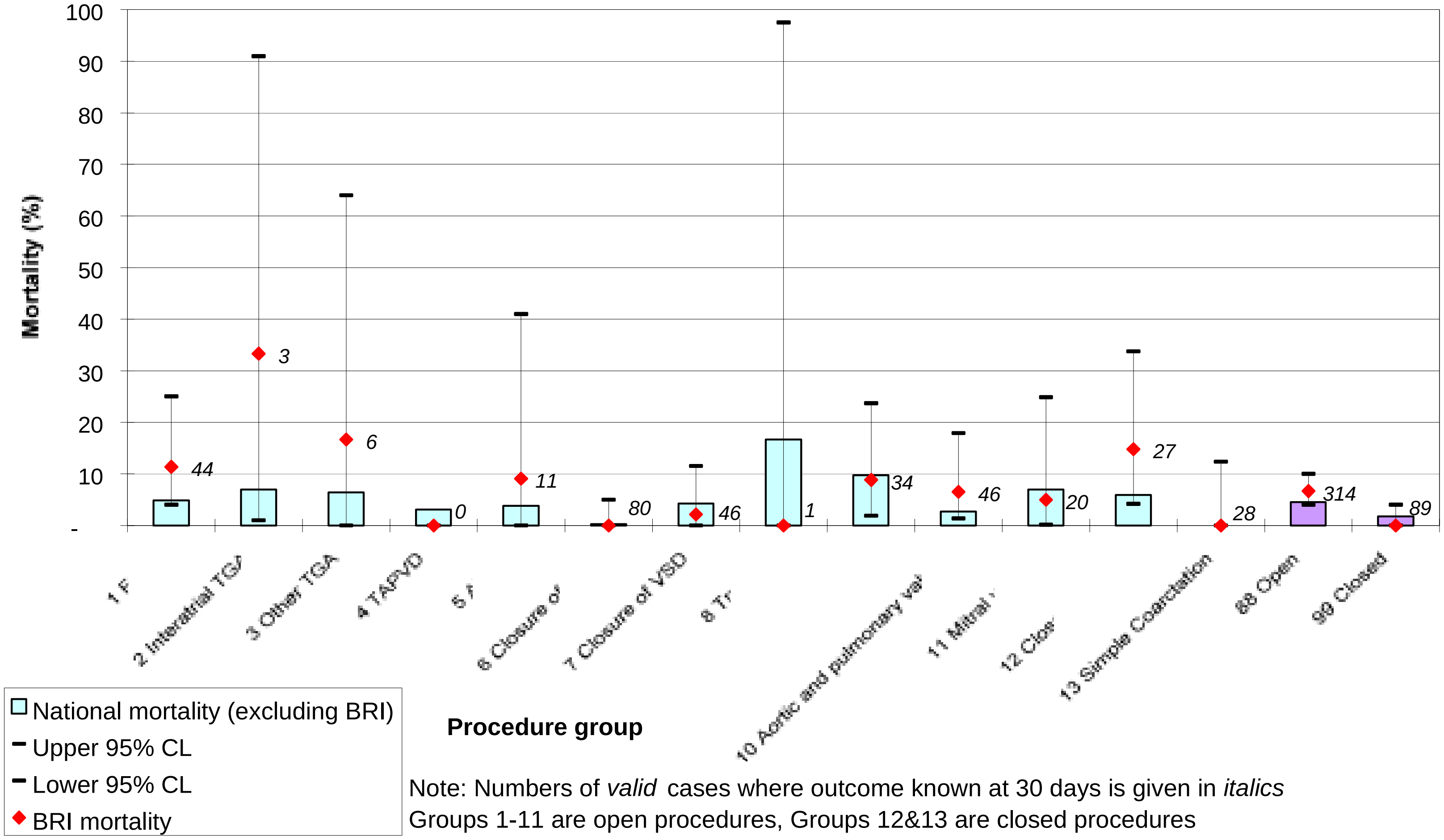


Figure 2.3 Comparison of mortality rates between UBHT and rest of the country - HES 1 April 1991 to 31 March 1995 - aged 90 days to 1 year



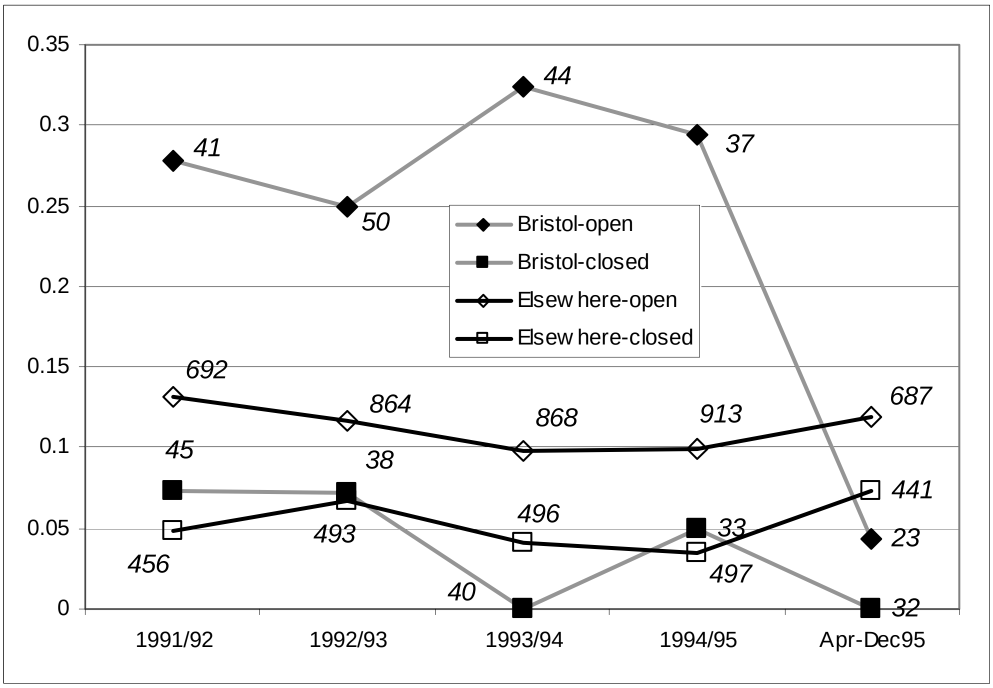
Note: Numbers of *valid* cases where outcome known at 30 days is given in *italics*
Groups 1-11 are open procedures, Groups 12&13 are closed procedures

Figure 2.4 Comparison of mortality rates between UBHT and rest of the country - HES 1 April 1991 to 31 March 1995 - age 1 to 15 years



Note: Numbers of *valid* cases where outcome known at 30 days is given in *italics*
Groups 1-11 are open procedures, Groups 12&13 are closed procedures

Figure 2.5 Annual mortality † for admissions involving open and closed procedures in children aged under 1 year (epoch 3 & 4)



† Mortality rates based on numbers of valid cases where outcome known at 30 days.
Total number of admissions is given in italics next to data points.

Figure 2.6 Simple Venn Diagram showing relationship between 13 procedure groups and open/closed classification

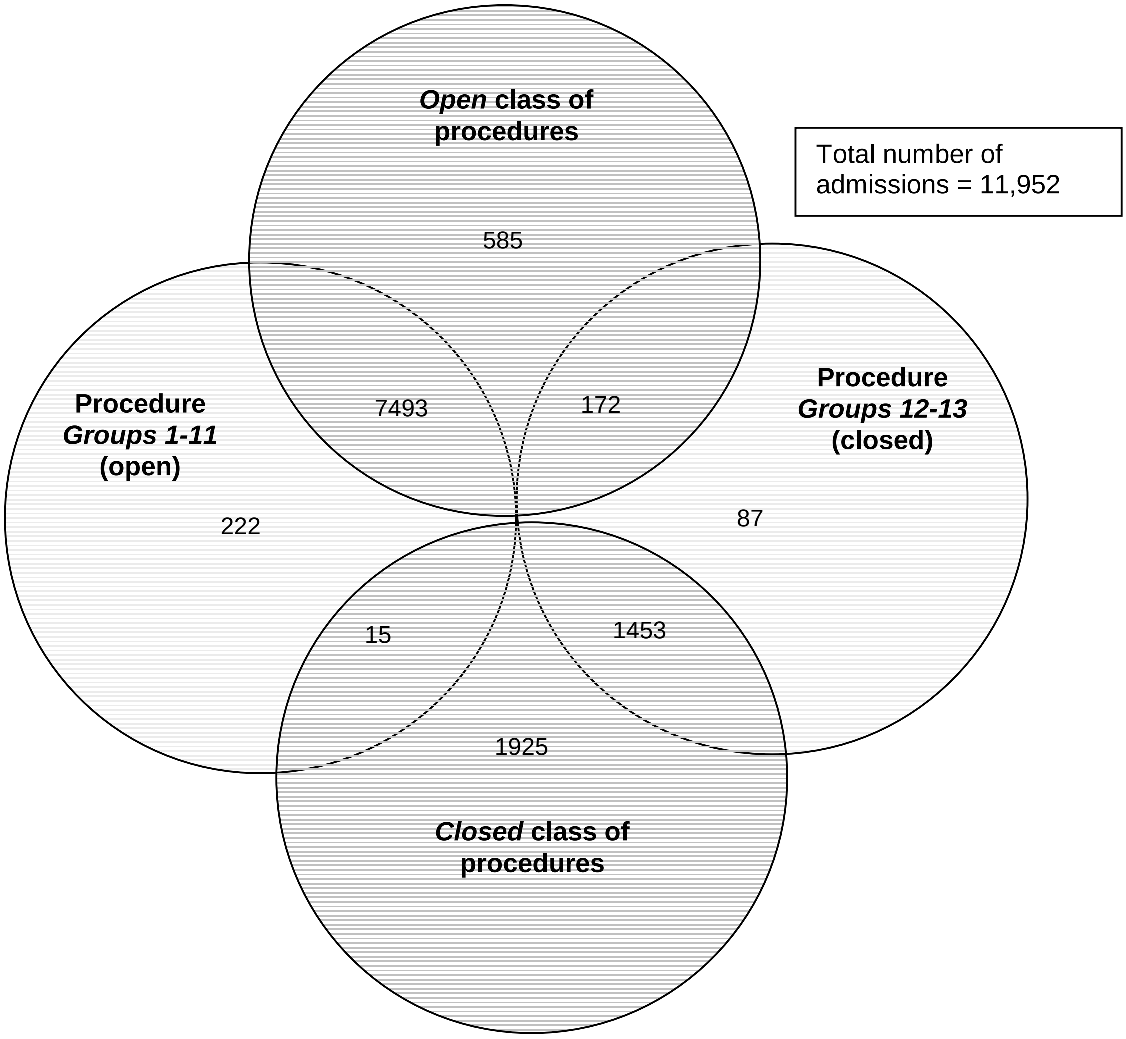


Figure 3.1 Probability distribution for the typical mortality rate for open and closed procedures in each age group estimated from the 11 centres excluding UBHT (shaded in solid grey) - plus probability distribution for the 'true' mortality rate in UBHT (hatched shading)

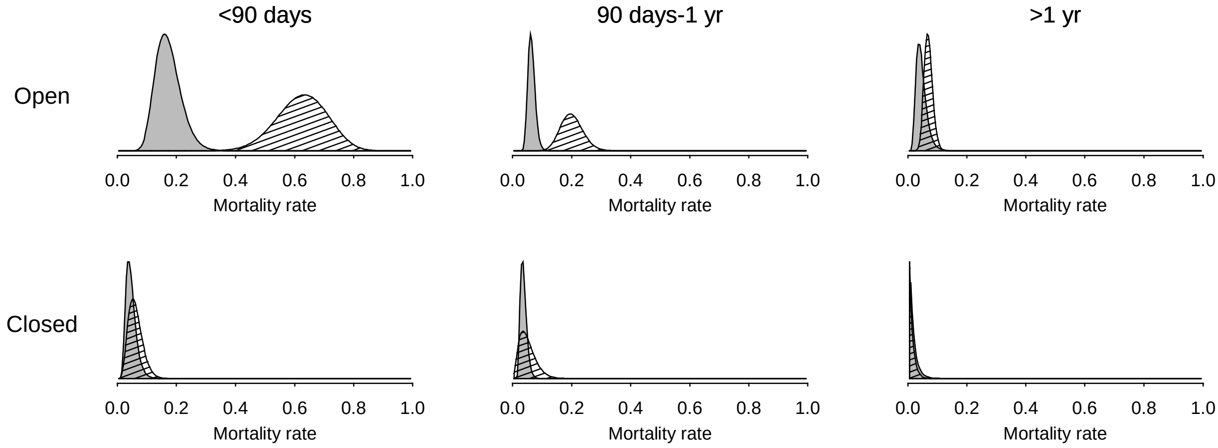
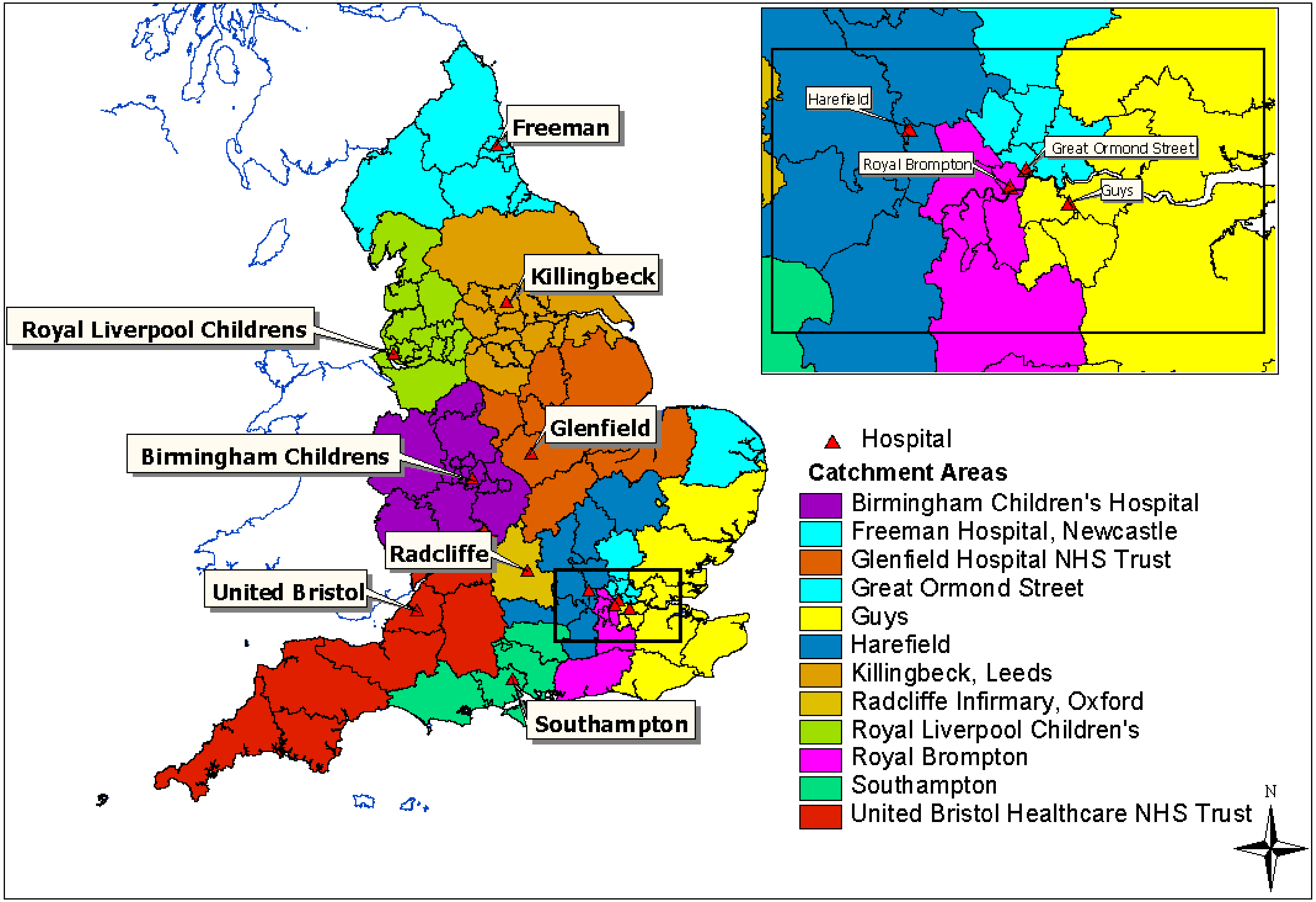
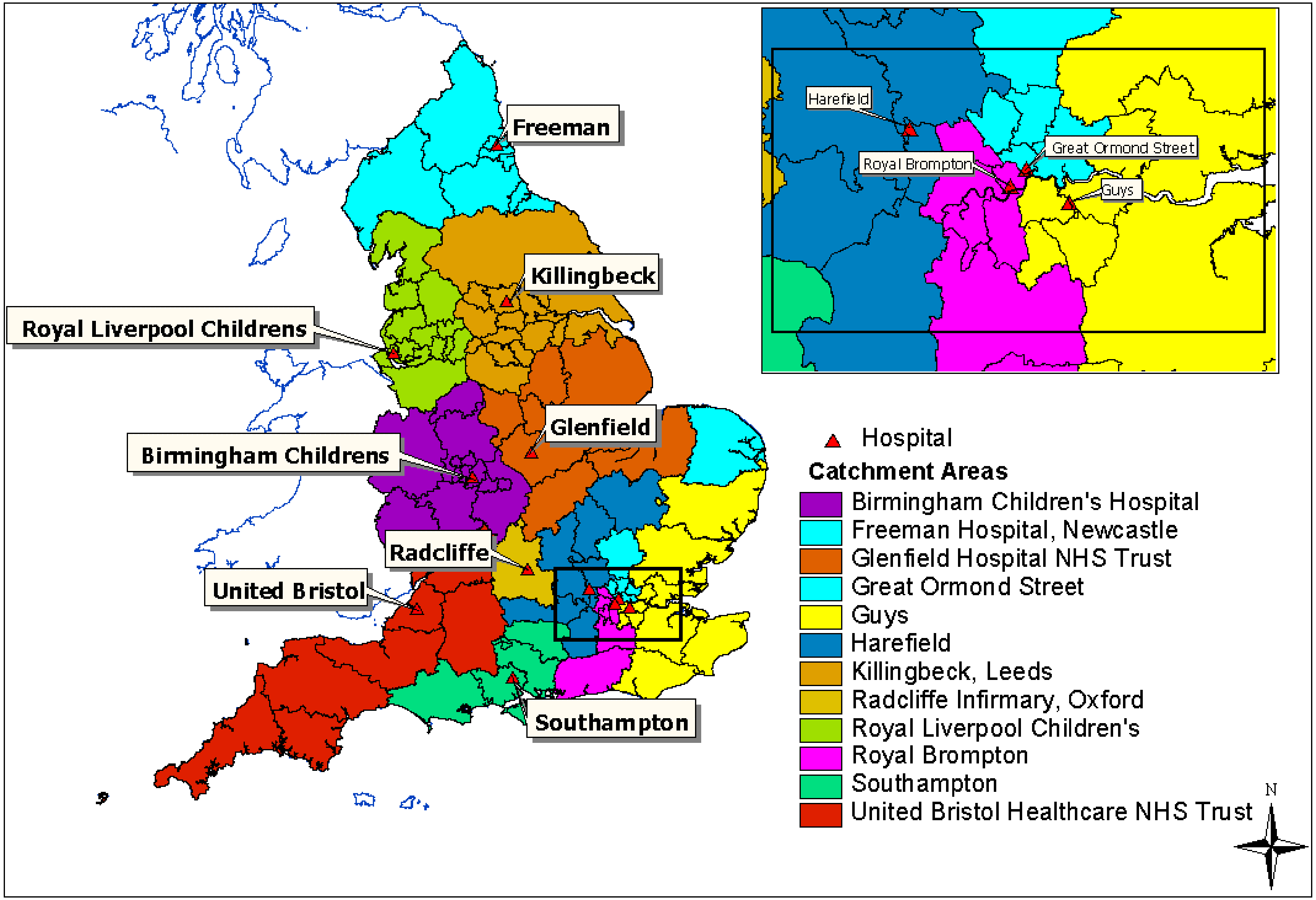


Figure 4.1 Empirical activity–based catchment areas† of hospitals in England (London, inset)



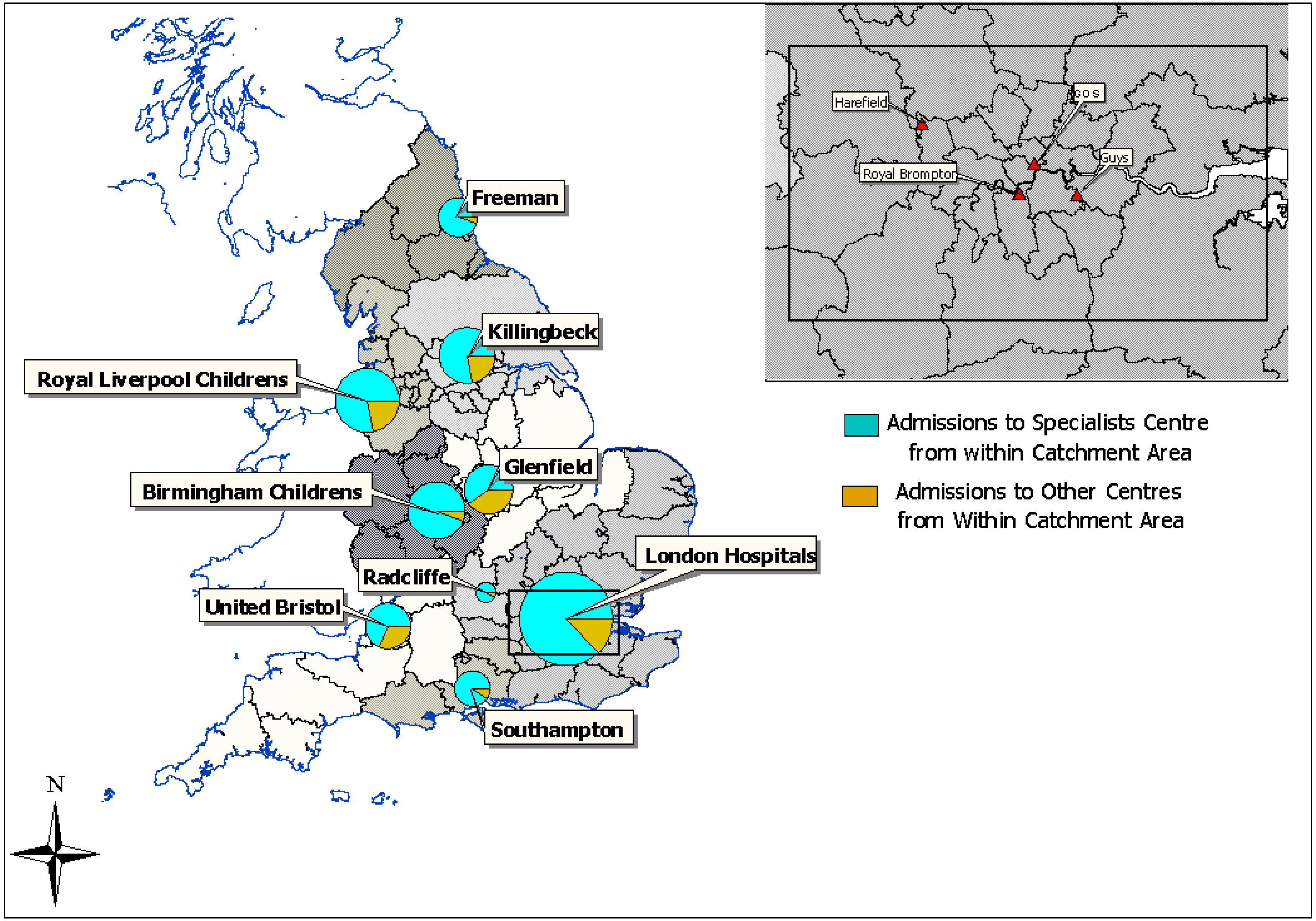
† The number of admissions from each HA (1996 boundaries) to each specialist centre was calculated for the 13 procedure groups combined and from the open or closed classes. Each health authority was then allocated to a specialist centre catchment area, according to the centre which undertook the largest proportion of operations of residents within that HA.

Figure 4.2 Geographical proximity–based catchment[†] areas of hospitals in England (London, inset)



[†] Geographical Information Software was used to determine the distance from the population centroid of each HA (1996 boundaries) to each specialist centre. Each HA was then allocated to the nearest specialist centre catchment area.

Figure 4.3 Map of admissions to specialist centres by geographical catchment areas† (London, inset), HES 1 April 1991 to 31 March 1995, age 0 to 15 years for all open/closed class and 13 procedure groups



† Geographical Information Software was used to determine the distance from the population centroid of each HA (1996 boundaries) to each specialist centre. Each HA was then allocated to the nearest specialist centre catchment area.

Appendix

Open and closed classifications

17-Aug-99

Procedures were described as open - closed - adult -
Either open or closed etc. by two of the expert advisors.

Procedures described as open or mostly open were classified as open
Procedures described as closed or mostly closed were classified as closed
Procedures were excluded if they were described as

- Adult
- Medical
- Either open or closed
- Unspecified

Open Procedures		**Closed Procedures**	**Excluded Procedures**	
K02.1	K34.1-9	K15.1-2	K16.1-8	L21.1
K04.1-4	K37.1-9	K15.8	K22.1-2	L21.2
K04.9	K53.1+2	K32.2-9	K22.9	L21.5
K05.1-2	L01.1	K61.1-4	K23.1	L21.8
K05.8-9	L01.2	K68.1	K23.3	L23.8+9
K06.1	L01.4	K68.2+8+9	K28.5	L25.8+9
K06.8	L05.1	K69.9	K29.5	L26.1-8
K07.1-3	L06.1+2	K71.2+8	K33.3	L37.8
K07.8-9	L09.1+8+9	L02.1-8	K35.2-8	L38.3
K09.1-6	L10.1+2	L07.1+2	K38.8	L38.4
K09.8-9	L10.3	L08.1-9	K40.4	L39.1
K10.1-5	L10.8+9	L06.3+5+6	K45.4	L39.4
K10.8-9	L11.1	L12.1+2	K47.2-9	L63.1+3+6
K11.1-5	L12.3+4	L23.1-5	K48.2+4	L71.1+3
K11.8-9	L12.8+9	L51.8	K51.1	L79.8
K12.1-3		L62.1+2+4	K54.3	L91.1-3
K14.1-2		L70.3	K55.2	L94.8
K18.2-5		L93.3+8	K55.8	L95.1
K18.8			K56.1	
K19.2-6			K57.1-8	
K19.8-9			K59.3	
K20.2			K60.1-9	
K20.8			K63.1-9	
K25.3-5			K65.1-9	
K25.8-9			K66.3+8+9	
K26.1-4			L03.1+8	
K26.5			L04.3	
K26.8-9			L05.2+3	
K27.3-8			L05.8	
K28.1			L06.8+9	
K28.8			L07.8+9	
K29.3			L13.1+3+8	
K30.1-8			L16.1	
K31.1-8			L19.2	

Statistical Appendix

This appendix describes the rationale and technical details behind the statistical methods used in Section 3 to compare individual performance in the 12 specialist centres. A specific objective of this analysis was to determine whether or not UBHT's performance diverges from other specialist centres, and if so, to determine the nature and extent of this divergence. The first goal of the statistical analysis therefore was to understand how performance varied between the other specialist centres; this would then allow us to assess whether the performance outcomes observed in UBHT could reasonably be assumed to fit into the pattern of variation seen for the other centres. For example, if the mortality rate in UBHT did not appear to be drawn from the same distribution as the mortality rates in the remaining centres, then we may conclude that UBHT's performance was divergent. This divergence is summarised by the excess mortality in UBHT, defined as the difference between the observed number of deaths and the expected number assuming the 'true' mortality rate in UBHT was typical of that in the other 11 centres.

Statistical quantification of 'typical' performance and between centre variability in performance for the other specialist centres

We carried out a multilevel (also termed a random effects or hierarchical or variance components) analysis of the 11 centres excluding UBHT in which the 'true' mortality rate in each centre is assumed to be drawn from some underlying distribution which is the same for all centres. The rationale behind this model is that we do not expect mortality rates in each centre to be identical, but for a given procedure and age group, it is reasonable to assume that all the centres would have similar mortality rates. This similarity is modelled statistically by assuming a common underlying probability distribution for the mortality rates in each centre. The mean or average mortality rate in this underlying distribution represents the mortality rate in a 'typical' centre (i.e. if we were asked to predict mortality in a new centre, in the absence of any other information about that centre, our best guess would be the average or typical mortality rate based on the other 11 centres). The variance of the underlying distribution tells us about the spread of plausible 'true' mortality rates we might expect amongst centres (i.e. we would expect the 'true' mortality rate in a new centre to fall somewhere within the plausible range of values indicated by this variance).

At this stage, it is helpful to introduce some notation to aid communication of the model:

c indexes centre, with $c = 1, \ldots, 12$ and $c = 1$ denoting UBHT.
a indexes age group, with $a = 1, 2, 3$ denoting under 90 days, 90 days to under 1yr and 1-15 years.
g indexes procedure group or operation class, with g = 1, …, 13 and 88, 99.
n_{cag} denotes number of admissions in centre c, age group a and procedure/class g
d_{cag} denotes number of deaths in centre c, age group a and procedure/class g
d_{cag} / n_{cag} denotes the observed mortality rate in centre c, age group a and procedure/class g
r_{cag} denotes the 'true' mortality rate in centre c, age group a and

procedure/class *g*
m_{ag} denotes the (logit transformed) mean of the underlying distribution of mortality rates across centres 2-11 for age group *a* and procedure/class *g*
v_{ag} denotes the variance of the underlying distribution of (logit transformed) mortality rates across centres 2-11 for age group *a* and procedure/class *g*

Since the observed mortality rate in a particular centre, age and procedure group may differ from its underlying 'true' value due to chance fluctuations, we first allow for this random variation by specifying a model relating the observed number of deaths to the 'true'mortality:

$$d_{cag} \sim \text{Binomial}(r_{cag}\ ,\ n_{cag})$$

where '~' means 'is distributed as'. This is the first level in our multilevel model. The second level is to specify the underlying distribution for the true mortality rates rcag. A common choice is to assume that the logit transformed mortality rate (i.e. the log odds of dying) for each centre follows a Normal distribution with unknown mean and variance:

$$\log[r_{cag} / (1 - r_{cag})] \sim \text{Normal}(m_{ag}, v_{ag})$$

We have adopted a Bayesian approach and so the third level of the model involves specifying prior distributions for the mean and variance of the underlying distribution of (logit transformed) mortality rates. These prior distributions represent our beliefs before we see any data about what we think the average mortality and variability across centres will be. Since we do not want our prior opinions to have much influence on the results of the analysis, we specify the following minimally informative prior for the average mortality (on the logit scale):

$$m_{ag} \sim \text{Normal}(0, 1000)$$

This is essentially equivalent to saying that a priori, all values of m_{ag} within a plausible range are equally likely. For the between-centre variances, we assume exchangeability across procedures/classes and age groups. That is, we assume that all the variances v_{ag}, a=1, …, 3; g=1,…13, 88, 99, are drawn from a common prior distribution with an unknown mean:

$$\log(v_{ag}) \sim \text{Normal}(\mu, 1)$$

Choosing an exchangeable prior for v_{ag} allows us to pool information on between-centre variability in mortality rates across procedures/classes and age groups. This means we obtain more reliable estimates of the variance components than if we had assumed independent prior distributions for each v_{ag}. In the latter case, our estimates for the between-centre variance in each strata *ag* would have been based only on the data for that strata, which are typically very sparse. We allow the mean, μ, of the prior distribution for $\log(v_{ag})$ to be unknown and assign it a Normal(0, 1000) hyperprior; this expresses virtual prior ignorance about the average value of the between-centre variances. We fix the prior variance of $\log(v_{ag})$ to be 1, which corresponds to the belief that there could be 50-fold (i.e. $e^{1.96*2*1}$) variation in the between-centre variability in mortality rates across 95% of the strata.

Inference for the above model yields a *posterior distribution* for the underlying mortality rate in a typical centre excluding UBHT, and for the variability in true mortality rates across these other centres.

Statistical assessment of whether UBHT is a true 'outlier'

UBHT could be said to be a true 'outlier' (i.e., divergent) if its performance does not appear to be drawn from the distribution from which the other centres are drawn, even after allowing for sampling error (i.e. random fluctuations between the observed and true mortality rate in UBHT) and variability between centres. We quantify this divergence by estimating the *predictive distribution* for the number of deaths expected in UBHT. This is based on the posterior distribution for the underlying mortality rates in the other 11 centres plus allowance for binomial sampling variation in the observed number of deaths in UBHT. We can then calculate the *excess mortality* in each procedure/class and age stratum for UBHT: this is given by the difference between the observed and predicted number of deaths.

Implementation

All analyses reported in Section 3 were carried out using Markov chain Monte Carlo simulation methods implemented in the WinBUGS software (http://www.mrc-bsu.cam.ac.uk). An example of the program code for estimating excess mortality can be provided on request.

Comparison of performance in each of the other specialist centres relative to the rest

The Inquiry's remit included a specific brief to differentiate the performance of each specialist centre relative to the others, rather than focusing simply on UBHT's performance relative to the rest. We therefore repeated the above analysis a further 11 times, leaving out each centre in turn and predicting the excess mortality in the excluded centre based on the typical mortality rate estimated from the remaining centres including UBHT.

Sensitivity analysis

We carried out a range of sensitivity analyses to the various modelling assumptions. These included a comparison between logistic-normal and beta random effects distributions for the centre-specific mortality rates, and between various log-normal and gamma prior distributions for the between-centre variance components v_{ag}. The final inference concerning excess mortality in UBHT was robust to all choices considered.

Ranking

Another way to compare relative performance across centres is to *rank* them on the basis of their mortality rates for each procedure/class and age group. It is widely accepted that ranks are a very imprecise measure of 'true' performance and that 'league tables' comparing institutional performance can be highly misleading.[1] However, ranks are an intuitively appealing and easily understood summary of relative performance, and modern Bayesian simulation methods provide a means of quantifying the lack of precision by allowing us to estimate uncertainty intervals around the rank given to each centre. We are then in a better position to judge whether any firm inference regarding relative performance can be drawn from these ranks. For example, by quantifying the uncertainty associated with each rank, we may then calculate the (posterior) probability that a centre's performance is genuinely ranked worst.

For the ranking analysis presented in Section 3 we report the rank order of observed mortality rates across centres for each procedure/class and age group. We then use the simulation procedure described by Marshall and Spiegelhalter [2] and implemented in the BUGS software to obtain uncertainty intervals about these ranks, and to calculate the probability that each centre's performance is genuinely ranked worst. The underlying statistical model assumes independent binomial distributions for the observed number of deaths in each centre and procedure/class and age strata, with flat prior distributions on the 'true' mortality rate in each centre:

$$d_{cag} \sim \text{Binomial}(r_{cag}\ ,\ n_{cag})$$
$$r_{cag} \sim \text{Uniform}(0,\ 1)$$

At each iteration of the simulation procedure, a random value for the 'true' mortality rate r_{cag} in each centre and strata is drawn from the distribution of plausible values. The latter distribution is determined by combining the binomial sampling distribution for the observed mortality (called the likelihood) with the uniform prior distribution for the 'true' mortality in that centre and strata. (Note that the prior distribution is flat or non-informative and so no subjective judgement has gone into these calculations). The set of simulated 'true' mortality rates from one iteration are then ranked across centres for each strata, and the process is repeated, in this case, 10 000 times. This yields a set of 10 000 plausible values for the rank of the true mortality rate in each centre by strata. The 2.5^{th} and 97.5^{th} percentiles of this distribution are used to provide a 95% interval for each rank; the proportion of the 10 000 simulated true mortality rates which were ranked highest across centres for a given strata gives the posterior probability that the centre is genuinely ranked worst for that strata.

Justification for adopting a Bayesian analysis

We have adopted a full probability (Bayesian) approach to the analyses reported in Section 3, using exact likelihoods and Markov chain Monte Carlo methods for inference. As far as possible, minimally informative prior distributions have been used and sensitivity analysis carried out to alternative prior assumptions. A similar analysis could have been carried out using non-Bayesian methods such as penalised quasi-likelihood.[3] However, one advantage of the Bayesian approach is that we were able to calculate exact (within Monte Carlo simulation error) interval estimates for the summary measures of interest (e.g. excess deaths, ranks) rather than relying on asymptotics as in a classical analysis. This is particularly important in the present situation, where many of the strata have small numbers.

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[1] Goldstein, H. and Spiegelhalter, D.J. (1996). League tables and their limitations: Statistical issues in comparisons of institutional performance. *Journal of the Royal Statistical Society, Series A*, **159**, 385-443.

[2] Marshall, E.C. and Spiegelhalter, D.J. (1998). League tables of *in vitro* fertilisation clinics: how confident can we be about the rankings? *British Medical Journal*, **316**, 1701-4.

[3] Goldstein, H. (1995). *Multilevel Statistical Models*. London: Arnold.