



Clinical Case Note Review:

A review of pre-operative, peri-operative and post-operative care in cardiac surgical services at Bristol Royal Hospital for Children

30 June 2016

1. Summary

The Care Quality Commission has undertaken an expert review of case notes of a group of children who underwent heart surgery at Bristol Royal Hospital for Children¹ between January 2012 and December 2014. This was in response to concerns about the service raised by families of some children treated there. The purpose of the review was to determine whether there was evidence of any systematic problems with pre-operative, operative and post-operative care in the service as currently provided.

The expert panel examined in detail every stage of the clinical pathway for each child. They found that the standard of care provided was within the expected level of quality and was comparable with other centres in the UK. They did not identify any case where the standard of care fell below the expected level. The quality of the documentation improved during the period under review, particularly after the establishment of dedicated high dependency facilities from October 2012 onwards. While no overall judgement about clinical outcomes could be made from the case note review itself, the National Institute for Cardiovascular Outcomes Research has reported that the 30 day survival for all heart surgery procedures at the hospital was within the expected range during the period reviewed.

The panel noted several examples of good practice and made recommendations for improvements that the service should consider.

2. Introduction

The Care Quality Commission (CQC) decided to undertake a review of case notes of children who have undergone surgery for congenital heart anomalies at Bristol Royal Hospital for Children after consultation with NHS England. The purpose of the review was to provide an assessment of current practice at the hospital. The review focuses on surgical interventions undertaken between January 2012 and December 2014. It was undertaken in two stages. Two nurses, with expertise in children's cardiac services, reviewed a number of records from this three year period to identify triggers which indicated that there had been unexpected clinical events during care. These cases were then reviewed by a team of clinical experts. From this list the expert panel selected a limited number of cases to be reviewed in detail. The panel individually and independently reviewed the case notes from this second group and then jointly discussed their findings to draw overall conclusions. This report presents the findings from the case note review with reference made to published guidance where this is relevant to the review methodology and findings.

¹ Bristol Royal Hospital for Children is part of University Hospital Bristol NHS Foundation Trust

3. Background

Concerns were raised by a number of families about the care of their children following cardiac surgery at the Bristol Royal Hospital for Children (BRHC) prompting the CQC to inspect the children's cardiac ward and paediatric intensive care unit at the hospital in September 2012. This inspection found insufficient numbers of experienced staff to provide high dependency care on ward 32. The CQC served a warning notice requiring improvement². An unannounced follow-up inspection in November 2012 reported improvements in nurse staffing, with adequate levels of suitably trained staff on ward 32 and high dependency provision on the paediatric intensive care unit³. A subsequent inspection in April 2013 found that the trust had taken action to ensure that children on ward 32 experienced care and treatment that met their needs. The trust opened a dedicated high dependency unit on ward 32 on a staged basis between April and September 2013.

In September 2014 the CQC carried out a comprehensive inspection of University Hospitals Bristol NHS Foundation Trust, which included the services provided by BRHC. Services for children and young people were rated as good overall, specifically good for safety, outstanding for effectiveness, good for caring, good for responsiveness and good for well-led.

Continuing concerns by families led to the commissioning of an independent review of the service by NHS England in 2014. This review is led by Eleanor Grey QC, with advice from Sir Ian Kennedy. At the same time, in consultation with NHS England, the Chief Inspector of Hospitals for the CQC agreed separately to review the clinical outcomes of the service with support from the National Institute for Cardiovascular Outcomes Research (NICOR) and to conduct a clinical case note review to assess the care provided by the service.

NICOR undertakes an annual National Congenital Heart Disease Audit, compiling data from all 14 children's specialist cardiac centres⁴. A rolling three yearly report is published each year covering all NHS and private paediatric and congenital heart disease procedures undertaken in centres within the UK and Republic of Ireland. Analysis of findings is based on all paediatric and congenital heart surgery and interventions undertaken between April 1st and March 31st of each year. When this case note audit commenced in January 2015, NICOR had identified that BRHC was achieving outcomes worse than the warning level for 30 day survival for one procedure, arterial shunt surgery, but was within the expected range for all other

² CQC (October 2012) Review of Compliance: University Hospitals Bristol NHS Foundation Trust, University Hospital of Bristol Main Site

³ CQC (December 2012) CQC Inspection Report: University Hospital of Bristol Main Site

⁴ <http://www.ucl.ac.uk/nicor/audits/congenital/reports>

procedures⁵. In addition, the report noted that the data quality for surgical case notes was below 90% in 2012 to 2013, based on a review of 20 sets of notes.

In their response to NICOR, BRHC indicated there were 6 deaths out of 27 patients who had undergone a palliative arterial shunt procedure, representing a 30-day survival of 77.8%. From an internal audit of arterial shunt procedures, the trust identified that four of these infants fell into high risk groups, including low birth weight and complex cardiac anatomy whilst the other two died at home from blocked shunts following discharge. The team have established home monitoring for these infants, resulting in no further deaths at home in this group. In addition, the frequency that arterial shunts are performed at BRHC has fallen over the last 15 years, as children with two ventricles, such as those with Tetralogy of Fallot, undergo a primary repair rather than palliative surgery wherever possible.

In April 2016 NICOR published a further report of outcomes for congenital heart surgery covering the years 2012 to 2015⁶. It concluded that for this period survival at 30 days following paediatric heart surgery was within the expected range for all specialist children's heart units. There were no alerts for any procedure at the BRHC for this period. For children under 16 years of age BRHC undertook 835 surgical procedures, survival at 30 days was 98.3%, which was within the expected range compared to other units.

4. Terms of reference

The terms of reference were reviewed by and discussed with the expert panel before being finalised. The purpose of the case note review was to identify any systematic problems with pre-operative, operative and post-operative care. The cases were to be selected for an appropriate period to represent current rather than historical practice. The methodology would allow the expert panel to recommend particular cases for review based on clinical criteria. These would be clinical problems indicated by deviations from the planned care pathway, clinical incidents or episodes of deterioration in a child's clinical condition. Case notes were to be selected to be reviewed in detail where such problems were identified, to determine whether the care provided was appropriate based on the information available. The pathway of care to be reviewed included: pre-operative assessment and investigation, surgical intervention, post-operative care and follow up after surgery. The terms of reference of the review indicated that the scope of the case note review should be guided by the findings of the NICOR report. The report of the case note review should identify areas for improvement in care and areas of good practice. The report would cover the overall care of the patients reviewed, but would not provide findings about the care of individual patients.

⁵ NICOR (2014) National Congenital Heart Disease Audit Report 2010 – 2013

⁶ NICOR (2015) National Congenital Heart Disease Audit Report 2012 – 2015

The final terms of reference included criteria for case selection and an outline of the process to guide methodology (appendix 1).

5. Methodology

The case note review project was led by a Specialist Advisor from CQC and overseen by the Deputy Chief Inspector of Hospitals, both with experience in children's congenital cardiac services. A project outline was produced, consisting of a two stage process; the first part was an audit of 42 sets of case notes, undertaken by the Project Lead and a second nurse experienced in children's critical care and cardiac services. The second stage of the review involved a team of experts independently and individually undertaking a detailed review of a sub-group of the 42 cases.

The CQC has stayed in close touch with the independent Bristol Review to ensure that the two reports are complementary. The Bristol Review has reviewed cases between 2010 and 2014, where parents have raised concerns. The CQC case note review examined cases between January 2012 and December 2014, prior to and after the establishment of a designated high dependency unit. Cases for review were selected using clinical criteria rather than because a concern had been raised. No cases were reviewed by both groups.

5.1 Selection of experts

Selection of experts to be involved in the review was undertaken by the Project Lead and Deputy Chief Inspector of Hospitals. Experts were selected from children's cardiac surgical centres across England, ensuring that no unit was represented twice, to enable assessment by individuals with a variety of experience of children's congenital cardiac services. The centres where the experts were based were:

- Birmingham Children's Hospital
- Evelina London Children's Hospital
- Royal Brompton Hospital
- Southampton University Hospitals
- University Hospitals Leicester

One children's critical care nurse worked with the Project Lead to review the initial case notes. The expert advisor team, who reviewed the case notes in more detail, comprised a paediatric cardiac surgeon, a paediatric cardiologist, a paediatric intensivist and a children's critical care nurse.

5.2 Case note selection

Case notes were selected from the three year period between January 2012, prior to provision of high dependency facilities at BRHC, and December 2014, immediately prior to the review commencing. During this period there were just over 800 surgical cases of which the review team selected 42 cases (approx. 5%) for inclusion in the

initial stage of the process. The team decided to exclude any cases that had been investigated by the Coroner, as these had been reviewed in depth. Therefore, cases were selected by the CQC review team based on the following criteria:

- There were 30 deaths during this period, of which 2 were not related to surgery and 5 were investigated by the Coroner, leaving 23 deaths to be included in the review.
- 20 matched cases were identified following identification by the trust of the first three matched defects and procedures occurring after each case that had resulted in death. The review team selected the closest match for each procedure out of each set of three cases.
- There were three cases where children died with no match for either defect or procedure and three cases were similar to more than one of the matched cases.
- Two additional cases were added, as the sample group did not include any cases of transposition of the great arteries, where an arterial switch procedure had been performed. This ensured that all major lesions were included in the sample.
- A final list of 45 cases was sent to the trust to make the notes available for review by the Project Lead and a children's critical care nurse. During the process of extracting the records, a further three cases were identified as undergoing review by the Coroner and were removed from the list.

This resulted in the final list consisting of 20 children who had died with 12 months of surgery, 20 matched cases plus two cases with transposition of the great arteries.

5.3 Case note audit and final case selection

The initial stage of case note audit involved a screening process which was undertaken between 15 June and 5 August 2015, using 'The Paediatric Trigger Tool'⁷. This tool was based on evidence of the value of trigger tool methodology and was developed by the NHS Institute of Innovation and Improvement with input from clinicians from children's hospitals within England and Scotland. It provides a structure for case note audit, to detect adverse events in paediatrics in all hospital types including specialist paediatric centres.

This stage of the process involved an onsite review of the full set of case notes, including intensive care observation charts and joint cardiac meeting minutes, which were provided separately to the patient records. The auditors were experienced at reviewing case notes and reviewed the records independently. Each auditor completed a trigger tool form for each case, noting the cause for the trigger in the comments column. The final scores for each case were collated by the Project Lead

⁷ http://www.institute.nhs.uk/safer_care/paediatric_safer_care/get_started.html

and discussed at an expert panel meeting to make the final selection of case notes for detailed review.

To reach the final selection, it was agreed that a quarter of the 42 cases would be reviewed in detail by the expert team. It was also agreed that those children with complex co-morbidities would not be included in the final group and one case was removed as the Project Lead was informed that this case was being reviewed by the Coroner. The final group were selected using three criteria:

- The trigger tool suggested that interventions had been required to sustain life.
- The group represented a spread of cardiac anomalies.
- In view of the NICOR analysis of outcomes, patients that had undergone palliative arterial shunt procedures were included.

The final group of 11 cases included children with hypoplastic left heart syndrome, atrioventricular septal defects including infants with trisomy 21, anomalous pulmonary venous drainage, atrial septal defect, pulmonary atresia, coarctation of the aorta, double outlet right ventricle, ventricular septal defect, pulmonary atresia/hypoplastic right heart and transposition of the great arteries. Three of these children had palliative arterial shunts operations, rather than primary repairs. Six of the children had died and five had survived.

5.4 Detailed review of the records

While stage one of the process was being completed a case note review tool was developed. This was based on a tool that had previously been used for the detailed review of paediatric case notes and the congenital heart disease pathway provided by the trust (appendix 3). The draft review tool was circulated to the team of experts for their comments and amended (appendix 2) prior to circulation for use with written guidance for completion.

Letters were sent to the families of the final group of children to inform them of the process and allow them the opportunity to ask questions or raise any concerns they had about the process. The families were given a date by which they should return comments prior to the records being circulated to the team of experts. Experts reviewed the records between December 2015 and February 2016 and returned an completed review form for each child. Information from the experts was collated for each child prior to an expert panel meeting in March 2016, when each case was discussed in detail and the findings agreed.

6. Findings

The findings below are discussed in relation to each element of the review tool to identify emerging themes arising from the case note review process. These themes are discussed in the conclusions to the report.

6.1 Admission

The admission process in the cases reviewed was judged to be satisfactory with examples of good practice noted in several cases. Four of the children under review were admitted as emergencies, two urgently and five for elective surgery. The care provided varied with the different modes of admission. The panel observed evidence of good practice for elective admissions with families provided with written information about their care and the planned procedure. Parents were copied into clinic letters to referring clinicians and general practitioners. In one case an elective procedure was cancelled after admission for operational reasons, but the child remained in hospital and surgery was undertaken during the same admission. Urgent and emergency admissions were inevitably less structured, with less evidence of written information provided. In these cases, there was evidence of discussion with families about the diagnosis and plan for management. Some infants had been diagnosed antenatally and were born in the neighbouring maternity unit. In these cases the transfer from the neonatal unit, while urgent was planned and demonstrated adherence to local guidelines for stabilisation prior to transfer. There were also examples of cases admitted from external hospitals, both as urgent and emergency admissions. Transfer procedures appeared satisfactory and there was evidence of good communication with referring centres.

6.2 Diagnosis

The observed quality of diagnosis was generally good. In nine of the eleven cases there was well documented evidence of effective multidisciplinary cardiac meetings to discuss individual cases and to plan their care. In difficult and complex cases there was evidence that appropriate advice and support was sought from other centres. There was good evidence of well documented parental counselling in cases of antenatal diagnosis, with shared care and the use of telemedicine in one case. One family was offered an interpreter to ensure understanding during these discussions but there was no evidence that this was taken up.

The panel did note examples in the case review series where in retrospect a better diagnosis of complex cases would have been valuable in planning the clinical management or predicting the risk of the planned surgical approach. However, the experts did not judge that in any of these cases the quality of diagnostic practice fell below the acceptable range. There were examples of excellent diagnostic practice in other cases.

6.3 Preparation for surgery

Preparation for surgery was satisfactory, with good evidence of discussion between professionals locally and at other centres. There was evidence that families were offered pre-operative visits to the ward and paediatric intensive care unit and that their views were taken into account in relation to surgery. There was evidence in some cases that families received information and support from the Cardiac Liaison Nurse in the pre-operative period, but this was not recorded in all cases. Few notes

contained written entries from the Cardiac Liaison Nurses of discussions and contact with parents, which the review team would recommend for effective communication across the team. The trust has subsequently explained that the Cardiac Liaison Nurses recorded their contacts and discussions with parents on a separate cardiac database rather than in the case notes.

Two particular aspects of preparation were not well documented in the records reviewed. Firstly, in the majority of cases the risk of surgery was not expressed in numerical form in the documentation of consent. This does not mean that it was not discussed, but the reviewers regard it as good practice for the surgeon to record the percentage risk of mortality or other major complication that they have discussed with the parents or carers in the record or on the signed consent form. This ensures that there is no ambiguity when a procedure is described as high risk or low risk. In two examples reviewed features of the individual child's condition meant that the surgical procedure would carry a higher risk than would normally be expected for this operation. It was unclear from the case notes whether this was discussed during the consent process.

The reviewers also commented that nursing plans for post-operative management of the child's pain were not well documented in the majority of cases. It is good practice to discuss this with the child (where appropriate) and the family pre-operatively.

In one of the cases reviewed consent for the operation was obtained not by the surgeon who undertook the operation, but by a colleague. This is not necessarily bad practice but the reason for it was not apparent from the record.

In two cases medication errors were noted, which delayed surgery by two days in one child. In both cases, the appropriate action was taken and documented in the patient records. There was evidence of an explanation and apology given by the staff concerned. Investigations were undertaken, with duty of candour recorded in one case⁸. Where additional action was required, there was evidence of action planning and monitoring with completion of actions.

6.4 Surgery

There were many examples in the cases reviewed of excellent surgical care. There were examples of highly complex procedures that were performed well with good outcomes. The case reviewers were not critical of the standard of surgery in any individual case. In one particularly complex case the operation undertaken was not what had been planned and it was not clear from the case notes the reason for this. The use of transoesophageal or epicardial echocardiography during surgery to review the cardiac function before completion of the operation is now considered good practice and it was used routinely in the cases reviewed. The reviewers commented that the recording of the findings of the investigation was often limited. In

⁸ The Duty of Candour regulation took effect in November 2014.

many cases it was described as “satisfactory” with no further qualification. The reviewers would recommend that a full echocardiography report is recorded under these circumstances as this would help with post-operative management in complex cases.

6.5 Post-operative care

The arrangements for high dependency care developed during the period under review. The trust created two high dependency beds in the intensive care unit in October 2012 and opened a dedicated high dependency unit on ward 32 during 2013. The reviewers noted that the quality of documentation of post-operative care improved markedly during the period of the review. The recording of ward rounds on the high dependency unit and the paediatric intensive care unit was good. There was excellent documentation of daily nursing records, especially in relation to the input by the critical care outreach team with clear evidence of appropriate use of the clinical escalation tool, Paediatric Early Warning Score (PEWS) and the clinical communication tool, Situation, Background, Assessment, Recommendation (SBAR). An area of concern arose as sometimes the case notes referred to members of staff by their first name only. This is not good practice and meant that the reviewers could not always be sure about who was involved and what their role was. Additionally pain and sedation scores were not always recorded, with frequent gaps in some cases making it difficult to determine whether changes in analgesia had been effective. Despite this, there were some examples of good practice relating to pain management with involvement of the pain team and use of nurse controlled analgesia in the high dependency unit.

There was evidence of good post-operative monitoring of cardiorespiratory, neurological and renal status and regular microbiology screening, with timely referral to other teams such as neurology.

In one case, there was evidence of a mains power and generator failure during cardiac surgery involving the uninterrupted power supply to theatre 3, which necessitated quick responses and decisions to maintain patient safety. The child returned to the paediatric intensive care unit and went back to theatre the following day. This incident was fully investigated and an action plan established to review all power supplies to the trust site and ensure all critical theatre equipment had a backup supply. In addition, the business continuity plan has been reviewed to ensure that all critical equipment across the trust has a backup supply.

The cases reviewed indicated that some very difficult clinical problems were managed well and overall, the reviewers had no significant criticisms of any individual child’s care.

6.6 Parent/carer support

On the whole, communication with parents was well documented, and was seen to improve over the period between 2012 and 2014, particularly in relation to consent

which became more detailed. There was evidence of frequent verbal communication with parents, both face to face and by telephone, in the immediate post-operative period and if the child was unstable. However, in a few cases, the content of the documented communication was limited to statements such as 'parents informed' or 'parents updated'. It is good practice to provide a brief summary of discussions, to enable the whole team to know what information has been provided to parents and avoid inconsistency in communication. In one case it was clear that a family was upset about inconsistent communication during their interaction with members of different teams. This was well documented by the clinical teams who recorded how they went to great lengths to address the family's concerns, but the subsequent discussion with managers was not recorded. This could have included agreements about future communication, important for all members of the team, which should have been documented.

There was good evidence of effective support for families as they came to terms with their child's illness and the treatment required, with referrals for additional support from the local and Welsh Cardiac Liaison Nurses, Play Specialist, Social Worker and the Chaplain. The reviewers felt that there was not as much evidence of families being given appropriate written information about diagnosis and management as they would expect, although more evidence that written material was provided was seen in later cases and in relation to bereavement support.

6.7 Discharge planning

There was good evidence of parental training and education where monitoring and alternative feeding was required by children at home. This training included assessment of competence, which was signed by trainer and parent. The areas covered by training included care of Hickman line, nasogastric feeding, monitoring on warfarin and enoxaparin and where necessary basic life support.

Discharge to referring centres was managed well, with good evidence of effective communication with the local clinical teams. Discharge summaries were detailed and there was evidence that parents were provided with copies of discharge letters. Discharge planning took into account the need for care closer to home, where ongoing hospital monitoring was required. Follow up was often in outreach clinics and not recorded in the Bristol records. There was evidence in several cases of good outreach nursing support maintaining contact with families after discharge and providing support and advice. This included liaison with the Welsh Cardiac Liaison Nurses to ensure support was in place prior to discharge. In only one case was discharge planning seen to be below the standard expected and this related to failure to include the recommendations of a speech and language therapist in discharge communication. It is important to ensure that input from all professionals involved with individual children is included in discharge planning to ensure that all needs are addressed.

6.8 Outcome

The cases examined by the case note review were selected on clinical criteria and the expert panel acknowledges that this is only a small series of patients. For these reasons the outcome for this group of patients cannot be taken as necessarily representative of the outcomes for children receiving care in this service. While six of the children whose care we reviewed died, others with complex and difficult conditions had good outcomes. The reviewers did not regard the observed outcome in any case to be outside the range they would expect in any equivalent children's cardiac service.

It was not clear from the records what information the families received after a child's death in all cases. However, there was evidence of an increasing focus on effective bereavement support of families in the latter part of the period of the review, with excellent practice observed in these later cases.

The reviewers regard the child death reviews recorded on the children who died to be of high quality and they commented that they covered all the relevant issues. There was evidence of involvement of all teams within BRHC and between BRHC and other centres in relation to child death reviews.

7. Conclusions

Overall the expert panel found the standard of care provided, as evidenced by the cases reviewed, to be within the expected level of quality and comparable with other centres in the UK.

The clinical panel noted that the findings changed during the period under review with more extensive documentation towards the later part of this period and particularly after the opening of a dedicated high dependency unit towards the end of 2012.

There was evidence of good practice, especially in relation to documentation with some excellent examples in the high dependency unit and paediatric intensive care unit and in relation to child death reviews.

There was evidence of thorough investigation of incidents, with documented explanations and apologies to families, including appropriate reference to duty of candour. Action plans agreed as a result of incidents were seen to be monitored and actions completed.

The expert panel noted that the methodology of this review meant that the majority of cases reviewed were complex conditions. There were no concerns about the management of any individual case reviewed. Individual outcomes for the patients reviewed were within the expert panel's expectations.

The panel relied upon the published analysis by NICOR to assess the outcomes for the service as a whole. NICOR reported that the 30 day survival for children operated on at BRHC for all cardiac surgical procedures was within the expected range for the period reviewed.

The panel considered that the case notes they reviewed did indicate that there were a number of areas where improvements could be made which would enhance provision of services for and communication with children and families. They would recommend that the service reviews the following areas of practice:

- Recording the percentage risk of mortality or other major complications discussed with parents or carers on consent forms.
- Provision of a formal report of transoesophageal or epicardial echocardiography performed during surgery.
- Recording pain and comfort scores in line with planned care and when pain relief is changed to evaluate practice
- Ensuring all discussions with parents are recorded to avoid inconsistency in communication. This includes communications with the Cardiac Liaison Nurses, who should record contacts with families in the patient records.
- Providing written material to families relating to diagnosis and recording this in the records.
- Ensuring that advice from all professionals involved with individual children is included in discharge planning to ensure that all needs are addressed.

Appendix 1

Case not review: Terms of reference

The following terms of reference were drafted for discussion with the case note review team prior to commencing the case note review:

- To review 40 sets of case notes of children who underwent cardiac surgery, between January 2012 and January 2015, to identify any systematic problems with pre-operative, operative and post-operative care. These might be indicated by deviations from the planned care pathway, clinical incidents or episodes of deterioration in the child's clinical condition.
- To review cases in detail where problems are identified, to determine whether the care provided was appropriate based on the information available in the case notes.
- The planned pathway of care includes: pre-operative assessment and investigation, surgical intervention, post-operative care and follow up after surgery.
- To report in writing the results of the case note review identifying areas for improvement in care and areas of good practice.
- The report will be completed by the end of the summer of 2015.

Criteria for selection of cases

Cases will be selected based on the following criteria:

- Children will have completed a pathway of care from pre-operative assessment to post-operative care between January 2012 and January 2015
- Cases selected will cover the age range treated within the children's hospital
- The cases will be representative of all surgeons operating on children within the BRHC
- Cases selected will not include those being reviewed by the independent review team
- All cases will have included admission to PICU
- The team of experts will specify the range of congenital defects to be included
- Case notes will be randomly selected by the project lead and discussed with the case note review team prior to final selection.

Process for case note review

The case note review will be conducted using the following process:

1. A team of experts will be established in April 2015 to undertake the case note review. This will include a paediatric cardiac surgeon, a paediatric cardiologist, a paediatric intensivist and an experienced paediatric cardiac surgical nurse.

2. The process will be led by a Project Manager with experience in children's cardiac surgery. This person will be responsible for collating the information arising from the case note review and producing a report for CQC.
3. The case note review team/process will be supported by staff within CQC and the trust in Bristol. These individuals will prepare notes for review and arrange for records to be sent to the expert reviewers as required.
4. The review will consist of five stages:
 - i) The review team will meet to agree terms of reference and the case note audit tool (to be provided)
 - ii) Two members of the case note review team will review all 40 sets of notes on site at BRHC. All cases where problems are identified will be forwarded to the experts for more detailed review.
 - iii) The expert reviewers will undertake a detailed examination of the selected case notes, based on the criteria identified in the case note audit form. Experts will review each case independently, recording findings on the audit forms, which will be returned to the project manager for collation.
 - iv) The collated information will be discussed by the team to determine whether there are any problems in the care provided at BRHC.
 - v) The report will be drafted and circulated to the experts for comment prior to being finalised and sent to CQC.

Appendix 2:

Clinical Cardiac Case Note Review Audit Form

Demographics

Case ID	<i>(Project case number between 1 & 45)</i>	Date of birth	
Gender		Age in months	<i>(at time of procedure)</i>

Admission details

Admission date	Ward HDU ICU <i>(circle appropriately)</i>	Length of admission in	<i>(days & hours)</i>
Source of referral	Foetal medicine or cardiology/ GP/A&E/OPD/NNU/External hospital/other <i>(please specify)</i>	Type of admission	Elective Emergency <i>(circle appropriately)</i>
Readmission within 30 days	Yes No <i>(circle appropriately)</i>	Reason for readmission	
Comments			

Diagnosis *(see local pathway at end of document)*

Primary Diagnosis		Secondary diagnosis	
Comorbidities		Time of diagnosis	Pre-natal Post-natal <i>(circle appropriately)</i>
Diagnostic procedures undertaken		Compliance with local pathway	Yes No <i>(circle appropriately)</i>
Evidence of explanation & discussion with parents/carer.	Yes No <i>(circle appropriately)</i>	Evidence parents provided with written information	Yes No <i>(circle appropriately)</i>
Referral to a Children's Cardiac CNS	Yes No <i>(circle appropriately)</i>	Appropriate counselling support	Yes No <i>(circle appropriately)</i>
Comments			

Preparation for procedures

Type of procedure	Open Closed (circle appropriately)	Evidence of discussion at Joint Cardiac Meeting	Yes No (circle appropriately)
Pre-operative clinic	Yes No (circle appropriately)	Pre-operative preparation & visit to service	Yes No (circle appropriately)
Pre-operative investigations complete	Yes No (circle appropriately & list)	Pre-operative medication given as required	Yes No (circle appropriately)
Pain management discussed (as appropriate)	Yes No (circle appropriately)	Evidence of informed consent	Yes No (circle appropriately)
Evidence of opportunity for parents /carers to ask questions.	Yes No (circle appropriately)	Evidence procedure cancelled	Yes No (circle appropriately) Reason: (specify)
Comments			

Procedure

Procedure undertaken		Time taken	(hours & minutes)
Bypass	Yes No (circle appropriately)	Time on bypass	
Cross clamp time		Anaesthetic events	Yes No (circle appropriately & list)
Surgical events	Yes No (circle appropriately & list)	Recovery events	Yes No (circle appropriately & list)
Comments			

Post-operative care

Evidence of appropriate monitoring	Yes No (<i>circle appropriately</i>)	Pharmacological support appropriate to procedure	Yes No (<i>circle appropriately</i>)
Pain relief provided with appropriate assessment of efficacy	Yes No (<i>circle appropriately</i>) Comments:	Evidence that changes in cardiac status were managed appropriately	Yes No (<i>circle appropriately</i>) Comments:
Evidence that changes in respiratory status were managed appropriately	Yes No (<i>circle appropriately</i>) Comments:	Evidence that fluid balance was monitored and managed appropriately	Yes No (<i>circle appropriately</i>) Comments:
Evidence that neurological status was monitored and managed appropriately	Yes No (<i>circle appropriately</i>) Comments:	Evidence that haematological parameters monitored and managed appropriately	Yes No (<i>circle appropriately</i>) Comments:
Evidence of explanations of care to parent/carer	Yes No (<i>circle appropriately</i>)	Evidence of monitoring for signs of infection	Yes No (<i>circle appropriately</i>) Comments:
Emergency events	Tamponade Yes No Cardiac arrest Yes No Chest opened Yes No Return to theatre Yes No Significant arrhythmia Yes No Other (please state) Yes No	Effective management of emergency event(s)	Yes No (<i>circle appropriately</i>) Comments:
Comments			

Parent/carer support

Evidence of regular discussion with parent/carer	Yes No (<i>circle appropriately</i>)	Content of discussions recorded in child's records	Yes No (<i>circle appropriately</i>)
Evidence of parental involvement in decision-making	Yes No (<i>circle appropriately</i>)	Local accommodation provided	Yes No (<i>circle appropriately</i>)
Access to CNS/ Psychologist/other outside the clinical team for support	Yes Not recorded (<i>circle appropriately</i>)	Written information relating to pain relief and ongoing care provided on discharge from hospital	Yes No (<i>circle appropriately</i>)
Evidence of bereavement support and counselling offered	Yes No (<i>circle appropriately</i>)	Evidence of post-death follow up appointment	Yes No (<i>circle appropriately</i>) Comment
Comments			

Discharge planning

Discharge summary: PICU	Yes No (<i>circle appropriately</i>)	Copy of discharge summary to parents	Yes No (<i>circle appropriately</i>)
Hospital	Yes No (<i>circle appropriately</i>)		
Evidence of discharge planning	Yes No (<i>circle appropriately</i>)	Information provided to parents/carers	Yes No (<i>circle appropriately</i>)
Information provided to local hospital (<i>where appropriate</i>)		Follow up review date planned	Yes No (<i>circle appropriately</i>)
Date for review given to parent/carer	Yes No (<i>circle appropriately</i>)	Evidence of provision of emergency advice	Yes No (<i>circle appropriately</i>)
Comments			

Outcome

Outcome	<i>(circle appropriately)</i> Discharged home Discharged to local hospital for ongoing care Neurological deficit Palliative care Death Other (<i>specify</i>)		
Comment			
Overall comments			

Clinical records	Completeness (comments)	Appropriately signed Yes No (<i>circle appropriately</i>)	Legible Yes No (<i>circle appropriately</i>)
M&M meeting	Case discussed Yes No (<i>circle appropriately</i>)	Conclusions drawn Yes No (<i>circle appropriately</i>)	Practice recommendations Yes No (<i>circle appropriately</i>)
Comments			

Signature-----

Name-----

Date-----

Appendix 3

The Congenital Heart Disease Pathway

The diagram below indicates the usual process a child's care will follow, from diagnosis, through to treatment and then to ongoing care.

