

Leeds Children's Heart Surgery Services Review

11 March 2014

Preface by Mike Bewick, NHS England deputy medical director

"We welcome the publication of these reports which reaffirm NHS England's commitment to safety, listening to families' experiences, acting decisively when necessary and openly sharing information to promote safe care for everyone.

The Leeds children's heart surgery services review was undertaken to address issues raised regarding the safety and quality of care at the Leeds Teaching Hospitals NHS Trust. A significant amount of work has been undertaken to establish an accurate picture of the services provided by the Trust, including a detailed review of cases and interviews with families to understand their experiences.

We are confident from the findings of *The Mortality Review* that clinical outcomes at the Trust are in line with other, similar heart surgery units in England. I am happy to say, on the basis of the evidence we currently have, that services at Leeds are safe and are running well.

There is significant learning that will be taken forward from *The Family Experience Report* and I would like to thank all of the families who felt able to share their difficult stories with us. I would assure them that NHS England will be working with the Trust and partner organisations to see that necessary changes are made.

Such experiences cannot be defended and I would look to the Trust to respond positively to this report. We must make sure that all those involved in the care of such vulnerable children heed the lessons and be able to reassure our communities that the high quality and compassionate care is provided at all times.

We must make sure that the families, who have had such a distressing experience, have not only been listened to but heard by the Trust locally and the NHS nationally. We look to commissioners, regulators and professional bodies to make sure all units learn from the personal testimony that these families have bravely shared with us.

A new national review is currently being undertaken of adult and children's congenital heart disease services. As part of this there will be a public consultation this summer on a set of proposed service standards that have been informed by engagement with patients and families and the learnings from Leeds will also form an important part of this."

A handwritten signature in black ink that reads 'Mike Bewick'.

Mike Bewick
Deputy Medical Director
NHS England

Introduction

NHS England is committed to upholding the NHS Constitution pledges of openness, transparency and candour. Equally, it values kindness and compassion in NHS staff as much as their technical skills. When concerns were raised about the care of congenital cardiac patients at Leeds Teaching Hospitals NHS Trust (LTHT), NHS England was bound to investigate. Working closely with the Trust and other relevant agencies including the NHS Trust Development Authority (NTDA) and Care Quality Commission (CQC), it has commissioned three review processes.

An externally-led review of staffing, internal procedures and governance took place in April 2013, and an externally-led mortality case review later in 2013. The evidence available to NHS England is that LTHT cardiac surgery unit provides medical and surgical care in line with standard practice. In addition, updated mortality statistics from the National Institute for Cardiovascular Outcomes Research database shows that this unit does not have an excessive mortality and is not an outlier with regard to other Units.

As part of its investigations, NHS England also commissioned a third review to look into the concerns being expressed by some of the families who used the Leeds cardiac unit. This report is published as *The Family Experience Report*. It evidences that 16 families, who came forward to be interviewed, had poor experiences of care from the Leeds Teaching Hospitals NHS Trust children's cardiology service.

We recognise that these concerns relate to care given to patients and families before April 2013, and the Trust has made changes since then, in its staffing, procedures, and leadership.

Although 16 families seems a small percentage of the hundreds of patients and families having treatment in this service every year, every patient and family is entitled to the highest possible standards of care. All feedback is therefore important and must be used to continually improve services.

NHS England and other agencies will ask the Trust to provide assurance that any required changes have been implemented and that the service continues to provide high quality care.

Patients and families should take reassurance from the evidence available to date that the service remains safe

Context and review process

Being told that your child has a congenital heart problem can be devastating, with profound consequences for every family member. Providing care to children and families in this situation requires technical competence, patient and family centred care, compassion and emotional support. Co-ordinated care by a multi-disciplinary team of medical nursing and therapy specialists, often working together over a large geographical network, is critical.

In recent years, great advances in the standards of care and the successes of operations and treatments for affected children have taken place.

On occasions, the care offered to children or families may fall below the standard that patients are entitled to. When this happens, it needs to be thoroughly investigated so that all lessons can be learnt, and all necessary improvements can be made.

During 2013 concerns were raised in relation to the quality of care offered to patients undergoing surgery for congenital cardiac conditions at Leeds Teaching Hospitals NHS Trust.

Concerns arose from three sources, namely:

- a) Mortality data released by the Director of the National Institute for Cardiovascular Outcomes Research (NICOR) in March 2013. The data gave a partially risk-adjusted analysis of patients who died in the 30 days after a surgical procedure and who were operated on in the years 2009 to 2012 and suggested a higher mortality rate in this Unit when compared to similar units in the country.
- b) Complaints and concerns expressed by families of children treated in the Unit which were reported to the CQC and NHS commissioners.
- c) Concerns expressed by another NHS Unit in relation to patient pathways and referrals to other units.

Because of these concerns, there was a temporary cessation of surgery commencing on 28 March 2013. NHS England convened an urgent Quality Surveillance Group (QSG) on 2 April 2013 and a subsequent Risk Summit on 4 April 2013. These meetings were held in line with national guidance for handling quality concerns in the NHS. They were led by NHS England and were attended by other agencies including the CQC, LTHT and the NTDA. It was agreed that a two-phase review of the children's cardiac surgery service in Leeds would be carried out.

The **first phase** of the review was a rapid review of Trust's children's cardiac surgery unit to ascertain if there were any identifiable significant or immediate safety concerns. This review took place 4-7 April 2013.

A team of external and independent specialists reviewed clinical governance processes, staffing capacity and capability, and elements of patient experience which included processes for complaint handling, referral management and patient pathways in and out of the unit. This review reported its findings and recommendations to a Risk Summit convened by NHS England on 8 April 2013. The report of this review has been published on the NHS England website¹.

This Risk Summit also received revised and updated NICOR mortality data which showed the Leeds unit to be no longer an outlier, but "*close to the alert line*". Following the assurance given by the first phase review report and by the revised mortality data, it was agreed by all parties that surgery would recommence, whilst the second phase of review took place.

¹ <http://www.england.nhs.uk/wp-content/uploads/2013/04/leeds-ext-review-rep.pdf>

The **second phase** of the review comprised three strands:

- A case note review of the child deaths that had occurred in the period from 2009 to 2012 which was the time period used in the collection of NICOR data (*Mortality Case Review*).
- An investigation of the experiences, views and concerns of parents and families (*The Family Experience Review*).
- An investigation of concerns being raised by other clinicians in relation to inter-unit transfers and patient pathways.

NHS England is now publishing the findings of the *Mortality Review* and the *Family Experience Review*.

The Family Experience Review

NHS England welcomes *The Family Experience Review*. We recognise that this gives the views of those 16 families who volunteered to give their accounts. We know that telling such deeply personal stories at a time of grief is difficult. We are grateful to the families for sharing their experiences.

The investigation and review were conducted by Professor Pat Cantrill, an independent case reviewer. The report was commissioned by NHS England on behalf of Quality Surveillance Group (QSG) and received at the QSG's meeting on 7 March 2014. Noting references related to cultural, equality and diversity challenges, the QSG asked for a further recommendation. The Trust has been asked to review and test the strength and appropriateness of its equality and diversity training.

The review has been shared with partner agencies as well as the Trust and will also be shared with the families who contributed ahead of publication.

The Mortality Case Review

It is recognised that undertaking a mortality case review is an established evidence-based tool for identifying lessons to be learned from the management of patients. The Trust was keen to work with NHS England to in order to reflect and learn from all instances where a child had died following surgery in the Unit from the start of the NICOR data collection period.

An independent externally-led review team, consisting of specialists from cardiology, intensive care and surgery, reviewed case notes. Following their review, a number of recommendations were made.

The report was also received at the Quality Surveillance Group (QSG) meeting on 7 March 2014. The report has been shared with the Trust and will be shared with the families whose cases were covered ahead of publication.

The overall finding was that medical and surgical care of patients, whose case notes were examined, was in line with standard practice.

Moving Forward

Reflecting the outcome of *The Family Experience Review* in particular, we conclude that these families did not get the level of care or service that they deserved, and for this we are truly sorry. Even though it appears to be a small number of families who have been adversely affected, we believe that every family counts. The experience of some families was not as it should have been, and certain protocols and audit programmes in the Unit must be further improved. There are clear lessons which should be learned.

NHS England has received reassurance from the Trust that prompt action has been taken in response to the findings and we look forward to seeing the outcomes of its improvements.

NHS England will now work with the Trust and other partner agencies to ensure that patients being treated at the Trust have the high quality and safe care they are entitled to expect.

As part of this, work is now underway with regard to exploring the governance of referrals in and out of the Trust and how the Trust works together with other hospitals in the best interests of patients.

NHS England
March 2014

***Children's Congenital Cardiac Surgery Services
at
Leeds Teaching Hospitals NHS Trust***

*Mortality Case Review
for the period 2009- 2013*

Overview Report

March 2014

Children's Congenital Cardiac Surgery Services
Leeds Teaching Hospitals NHS Trust

Mortality Case Review for the period 2009 – 2013: Overview Report

Contents

	Page
Executive Summary	3
Background	4
Methodology	5
Findings	5
Recommendations	9
Overall Conclusion	12
Appendix 1 -Terms of reference	13

Children's Congenital Cardiac Surgery Service
Leeds Teaching Hospitals NHS Trust:

Mortality Case Review for the period 2009 - 2013

Executive Summary

This review represents part of an overall review of the children's cardiac surgery services provided by Leeds Teaching Hospital NHS Trust (LTHT). It follows an earlier rapid review of the children's cardiac unit which focused on governance, patient pathways and procedures within the unit.

The mortality review was prompted following the release of draft data analysis by the National Institute for Cardiovascular Outcomes Research (NICOR) in March 2013.

The review was commissioned by NHS England and Leeds Teaching Hospitals NHS Trust and was conducted by an external and independent team of specialists. The review analysed the care provided to the 24 patients who died in the 30 days following a primary surgical procedure and which were included in the NICOR 2009 – 2012 data analysis. In addition the team reviewed the care given to those children who had died within 30 days of a primary cardiac surgery procedure from 2012 up to the time of the review.

A total of 35 children's deaths occurring during the period 2009 to 2013 were reviewed.

Within the context and remit of this review, the team found that the clinical management of the cases examined demonstrated medical and surgical care to be in line with standard practice. The review team have proposed a number of recommendations, principally in relation to the development of standardised protocols and further audits to be undertaken. These represent opportunities for further quality improvement in the unit.

Dr Damian Riley
Medical Director NHS England (West Yorkshire)
on behalf of the Review Team

March 2014

Children's Congenital Cardiac Surgery Service
Leeds Teaching Hospitals NHS Trust:

Mortality Case Review for the period 2009 - 2013

1. Background

- 1.1. During 2013 concerns were raised in relation to the quality of care offered to patients undergoing surgery for congenital cardiac conditions at Leeds Teaching Hospitals NHS Trust ("LTHT").
- 1.2. The concerns arose from three sources:
 - a) Mortality data released by the Director of the National Institute for Cardiovascular Outcomes Research ("NICOR") in March 2013. The data gave a partially risk-adjusted analysis of patients who died in the 30 days after a surgical procedure and who were operated on in the years 2009 to 2012.
 - b) Complaints and concerns expressed by families of children treated in the Unit and reported to the Care Quality Commission and NHS Commissioners.
 - c) Concerns relating to patient care which had been expressed by another NHS Trust.
- 1.3. The initial data released by the NICOR Director, appeared to show that LTHT children's cardiac surgery unit had a mortality rate 2.75 times greater than the national average. This led to a temporary cessation of surgery commencing 28th March 2013. Following a Risk Summit convened by NHS England on 4th April 2013, it was agreed that investigation of the concerns relating to the LTHT Unit would be undertaken and that as part of this process, there would be a case review of all children's deaths which accounted for the NICOR 2009-2012 data.
- 1.4. During April 2013, at the request of NHS England, NICOR provided an updated analysis of paediatric cardiac surgical mortality in England and Wales for 2009-2012. The analysis used a new case-mix adjustment methodology known as PRAiS (Partial Risk Adjustment in Surgery). Mortality for this data analysis was defined as a death within 30 days after a primary surgical procedure, and the first surgical procedure or operation performed is that which is logged on the NICOR database. The analysis was made available on the NICOR internet site and is found at: http://www.ucl.ac.uk/nicor/nicor/NICOR_statement_paediatric_cardiac_surgery
- 1.5. The updated analysis by NICOR revealed no statistically significant outliers in terms of mortality over the three year period 2009-2012 at any of the units in England, including LTHT. The Leeds Unit and two other children's heart surgery units were identified as lying "close to the 'alert' threshold" on the analysis graph. In their report, NICOR stated "*These findings do not indicate a safety problem in any centre....However, centres with 3 year outcomes approaching the alert threshold may deserve additional scrutiny and monitoring of current performance.*"

- 1.6. The purpose of the mortality case review was to examine the quality of medical and surgical care provided to those children who died following surgery during the reference time period, to give an opinion on the care provided and to identify any relevant learning or recommendations for further improvement in the quality of care provided.
- 1.7. The review examined the cases of 24 children whose deaths were included by NICOR in their comparative 2009-2012 data analysis. A further eleven cases of children were reviewed. These were children identified by LTHT who had died within the 30 day period after a primary surgical procedure in the years 2012 and 2013 up to the time of the review. As a result, 35 cases were reviewed in total.

2. Methodology

- 2.1. An expert external review team comprised of a congenital cardiac surgeon, a children's congenital cardiologist, and a paediatric intensivist, was established. They declared no conflict of interest. The review team were joined by the NHS England (West Yorkshire) Medical Director and the LTHT Medical Director (Quality and Governance) in undertaking the review process who declared no conflict other than their role in their employing organisations.
- 2.2. Each of the cases included as part of this review were analysed individually and the findings and recommendations were collated in order to produce the findings outlined below
- 2.3. For 30 patient cases the team reviewed the clinical case notes, relevant imaging, minutes of discussions at multidisciplinary case conferences and details from presentations and the conclusions reached at the LTHT unit's clinical governance meetings. For the additional five cases whose deaths occurred in 2013 a review of case conference minutes and clinical governance presentations took place. No new or additional findings, concerns or recommendations arose from the overview of these additional cases. The issues arising from these cases are thus integrated into the relevant sections of the report.
- 2.4. Interviews were held with the lead surgeon and lead cardiologist. It was noted that there had been changes to both staffing and the approach to case management within the unit over the reference time period.

3. Findings

3.1. General overview:

The review team formed an overview by analysis of case mix and complexity, and judged their findings against what was considered by the review team to be best practice. For some aspects of patient care there is no universally adopted national guideline or protocol which is used consistently by comparable surgical

units. In such circumstance care standards were judged against perceived best practice in the opinion and clinical experience of the review team specialists.

Overview findings were:

- a) Within the context and remit of this review, clinical management of the cases examined showed medical and surgical care to be in line with standard practice.
- b) That the case-mix of surgical conditions and patients operated on in this cohort was in-keeping with comparable children's cardiac surgical units in the UK.
- c) That cases reviewed were predominantly of high or significant complexity often with additional contributory risk factors.

3.2. An analysis by way of thematic grouping of findings

In collating the findings some recurrent issues regarding case management are identified as 'themes'. Many of the themes identified were apparent in only a minority of cases, other than where specified in this report. Themes identified by the team were:

- a) In the majority of cases the operation appeared to have been undertaken on a weekday, with the case being the first on the operating schedule.
- b) In several cases the patient's prognosis was poor due to contributory and complexity factors and a fatal outcome may well have occurred in any comparable surgical unit.
- c) In a small number of cases operations were performed on extremely high risk patients with a likelihood of very poor outcome, and there was evidence that there had been appropriate parental counselling in this regard and the operation had been undertaken in light of the parents' views.
- d) In some records it was easy to identify the risk that had been quoted and discussed with parents, whilst in other notes there was no indication of the risk that had been conveyed to parents. Discrete parental communication logs were not maintained as routine in unit notes.
- e) In a small number of cases death was due to non-surgical causes which may have arisen coincidentally or may have arisen as a result of predisposition as a result of a cardiac arrest or prolonged low cardiac output peri and post-operatively. Examples of this include those children who died of necrotising enterocolitis.
- f) In some cases of particularly complex surgery operating time (and/or time on bypass and cross-clamping) appeared long, with some operations lasting

several hours. It was not clear how or if this is monitored by the unit, or if the unit had a protocol to relieve surgeons undertaking long operations. In some cases the operative note did not give sufficient detail to account for the long documented bypass or cross-clamp times. The review team did not have access to comparative data for surviving cases in the unit for benchmarking purposes and noted that benchmark data from other units on monitoring length of operations was not routinely available.

- g) In all but two of the cases, the surgical procedure performed was that which was planned by the case conference. This suggested that appropriate pre-operative diagnosis had been made. In the two cases where a different surgical procedure had been carried out during the operation, the surgeon made justification in the operative note.
- h) There was inconsistency in style and operative detail documented by surgeons in operation notes.
- i) Extracorporeal membrane oxygenation (ECMO) was used post operatively with appropriate indication and justification. In some cases however, its use was only after a cardiac arrest. There did not appear to be a unit protocol governing the use of ECMO.
- j) In a number of cases echocardiogram reports were not filed electronically or in standard format in the patient notes where they had been done post operatively on the intensive care unit by medical staff.
- k) Of the cases reviewed from 2009-2012, two were deaths following operations known as 'transposition switches'. In the cohort of the additional cases reviewed from the time period 2012-2013, there were two patient deaths after a 'switch' operation. One operation had been performed as an emergency after the sudden deterioration of the patient, and one patient death occurred following a 'complex switch' procedure. The review team noted that national benchmarking shows the unit to be within the normal parameters for mortality relating to transposition switch procedures on published data up to 2012. Whilst such clustering as noted in 2012-13 could be expected to occur in a unit of this size, on-going rigorous audit and statistical analysis over a longer time will be required to identify if such a cluster effect actually exists and if switch mortality remains within the expected parameters.

3.3. Findings in relation to individual surgeons:

- a) Evidence of team working was found in operation notes with two of the consultant surgeons commonly operating together, and of one consultant surgeon appropriately asking a colleague to assist in cases of complexity where a joint approach was agreed.
- b) A child was taken to theatre by one surgeon on three successive occasions over a short period of time without evidence that the opinion or support of another surgical colleague had been sought. It was not clear what arrangements for team work, cover or support were in this case.

- c) In one procedure, the operation note indicated that the operation was difficult and long, but gave no indication that assistance from a surgical colleague was sought by the lead surgeon. Furthermore it was not clear from the notes why the particular operative technique used to undertake the procedure was chosen. LTHT were made aware of this finding immediately.
- d) There were three deaths in three consecutive months during 2010 for a particular procedure undertaken by one surgeon without it being clear how LTHT responded or what support was offered to the surgeon.
- e) One operation note did not appear to match the procedure which had been performed and as reported to the clinical governance meeting. This has been reported formally to LTHT.

3.4. Specific findings in relation to protocol guided care:

- a) The unit protocol for aspirin anti-platelet mono-therapy for post-shunt care which was provided to the review team appeared to adequately document therapy but it had not been reviewed since 2011. It was not clear if it had been formally ratified for on-going use by LTHT.
- b) The review team observed an inconsistent approach to the use of intra-operative echo or 'exit-echo' before the patient left the operating theatre.
- c) The review team was aware that the unit is a centre for interventional cardiology and this was reflected in the later years of the review period by surgical conference meetings discussing options for non-surgical intervention, specifically in relation to the use of duct stents inserted via cardiac catheter as opposed to surgically inserted shunts. The review team did not see evidence of a unit protocol for decisions relating to the use of ductal stenting in such cases.

3.5. Other Comments and Findings:

- a) It was noted by the review team that in the majority of occasions where deaths were notified to the Coroner, there was no post-mortem arranged by the Coroner. This aspect of process was outside the remit of the review.
- b) Dual (two-surgeon) operating was evident in some cases as noted in the operation note. It is not evident that this information is routinely captured in local or national audits by such units and therefore attributing events or surgical outcomes to an individual may be misleading. The review team believe that the potential benefits of dual operating are considerable and thus appropriate recording in databases may be relevant.
- c) There is no national standard mortality review template for audit or analysis in undertaking this type of work, and an implementation of such a template could lead to standardising the audit of relevant clinical and clerical pre-operative, peri-operative and post-operative factors.

4. Recommendations

- 4.1 In the context of identifying opportunities for on-going quality improvement in this unit, the review team have made a number of recommendations. Many of these recommendations could apply more widely across other children's cardiac units in the NHS.
- 4.2 The recommendations arising from the findings of the review have been collated and grouped in relation to the themes identified. The recommendations are shown in Table 1 and Table 2. Each of these recommendations has been formed from the analysis and review of one or more cases. The suggested priority is an indicative ranking based on the opinion of members of the review panel.
- 4.3 Several recommendations are made in relation to standardising the processes and protocols operational in this and other units. It is recognised by the Review Team that an undisputed evidence base for some of these may be lacking, but the adoption of a standardised unit approach could enhance staff training, audit, cost effectiveness and inter-unit comparability.
- 4.4 Additionally, the review team considered that a range of further audits should be undertaken in order to facilitate the on-going quality analysis and development of the unit. Audits conducted by the unit should include a focus on bypass and cross-clamp times during operations to allow a comparison of non-survival and survival cases, as well as a focus on simple versus complex transposition surgery outcomes, allowing these to be benchmarked against national standards. This will allow organisational issues such as timing of procedures, staffing, cardiological and surgical expertise to be further evaluated.

Table 1: Recommendations for service development

<i>The review team recommends that LTHT and the Unit's clinicians develop the following:</i>	<i>Reference to findings</i>	<i>Suggested priority:</i>
a) A log of parental communications, to be kept in all patient records, which includes where necessary an indication of surgical risk and with whom it was discussed.	3.2(d)	Medium
b) A consistent unit approach to exit-echo before leaving theatre	3.4(b)	High
c) A re-refresh of the unit policy for post-shunt anticoagulation regimes, taking into account the audit results of other Units and all available evidence bases	3.4(a)	Medium
d) A consistent unit approach and audit of use of ECMO post op looking at timing of ECMO, to ensure the Unit can demonstrate a proactive approach	3.2(i)	Medium
e) A consistent unit approach to surgeon respite during long operations	3.3 (a-d)	Medium
f) A unit protocol for ductal stenting versus surgical shunting	3.4(c)	High
g) A unit protocol making explicit the approach to selecting the timing of undertaking palliative procedures, including septectomy, Glenn, and the Fontan procedure as a completion procedure for total cavo-pulmonary connection shunting and for responding to rising right sided pressures	3.1(d)	Medium
h) A consistent unit approach to recording operation details in the operation note	3.2(h) 3.3(e)	Medium
i) All echocardiogram reports should be filed in the notes in a standardised way that allows timely access by all relevant clinicians.	3.2(j)	low

Table 2: Recommendations for audit programme development

<i>The review team recommends that LTHT and the Unit consider the following audit programmes:</i>	<i>Reference to findings</i>	<i>Suggested priority:</i>
a) An audit of the surgical and team-working performance of the surgeon for whom specific case-issues were identified	3.3(b-d)	Medium
b) A wider audit of operating times, bypass times and cross-clamping times, comparing to acceptable norms, and identifying procedural and training responses to long times. This could inform any further analysis of the longer operating times as a contributory factor to mortality and determine if any action is needed. National collection and publication of such data may be required to achieve this.	3.2(f)	High
c) A refined procedure-specific outcomes audit, to demonstrate the caseload of the unit and the proportion of cases where outcomes are good. This should include a focus on simple and complex transposition surgery outcomes, and continue to be benchmarked against national standards, allowing organisational and timing issues to be monitored.	3.1(c)	Medium
d) Dual surgeon operating to be captured on local and national databases	3.5(b)	Medium
e) A standardised mortality review template is developed for national use in this specialist field	3.5(c)	Low

5. Overall Conclusion

- 5.1 The review of the clinical management in the cases examined showed the medical and surgical care to be in line with standard practice.
- 5.2 Recommendations for ongoing quality improvement have been identified for attention by LTHT and the Unit. These have been graded in the opinion of the review team as “high” or “medium” or “low” priority.
- 5.3 Leeds Teaching Hospitals NHS Trust is asked to give consideration to the recommendations in this report.

Leeds Teaching Hospital Trust Children's Heart Surgery Mortality Review

June 2013

Terms of Reference

Dated 7th June 2013

This is a jointly agreed and commissioned external review on behalf of Leeds Teaching Hospitals (LTHT) and NHS England which will report to LTHT and NHS England

Summary Purpose:

The purpose of this mortality review is to examine the quality of care afforded to those patients who died and provide a professional expert opinion on the medical standard of care.

Remit:

With regard to the surgery performed in Leeds on children up to and including 16 years of age for congenital cardiac conditions

- to review and comment upon the quality of care delivered to those patients who died following surgical intervention from 2009 to 2012 focusing on the cohort of cases used to create the PRAiS comparative data analysis released by NICOR
- to review and comment on the process of mortality review undertaken as part of the Unit's Clinical Governance Mortality and Morbidity Review Meetings
- to identify any additional learning opportunities (over and above the outcome of the specialty level mortality review) on the said cases

Review team

- **Mr Ken MacArthur:** Consultant Surgeon, Royal Hospital for Sick Children, Glasgow
- **Dr Jo De-Giovanni:** Consultant Cardiologist, Birmingham Children's Hospital NHS Foundation Trust
- **Professor Ian Murdoch:** Paediatric Intensivist, Guys and St Thomas's NHS Foundation Trust
- **Dr Damian Riley:** Medical Director, NHS England (West Yorkshire)
- **Dr A Bryan Gill:** Acting Medical Director (Quality and Governance), Leeds Teaching Hospitals NHS Trust

With support from

- **Alison Dickinson:** Programme Manager NHS England (West Yorkshire)

Objectives:

With regard to the identified cohort of children operated on in the Unit since April 2009 and who died within 30 days of surgery:

- To assess the clinical quality of care for patients who have died following surgical intervention, so as to identify factors contributing to or causing the death of the child including pre-operative, peri-operative and post-operative care, and evidence of communication and risk assessment to families
- To establish if the Unit, through clinical governance processes then identified and where appropriate implemented the relevant learning opportunities as part of the internal mortality review process

Principles:

- The review is to provide assurance that the quality of care was to a professionally accepted standard
- The review is jointly commissioned by NHS England and Leeds Teaching Hospitals NHS Trust
- Patient identifiable information shall not be included in the report.
- Serious concerns and risks to patient safety are to be notified without delay to the Medical Directors of NHS England & Leeds Teaching Hospitals NHS Trust
- Media relations and communications with stakeholders is conducted through the commissioners of this review

Data Source for review

- Patient case notes for 30 children's congenital cardiac surgical deaths from 2009 to 2012 (as used in the PRAIS database) and in addition surgical 30-day mortality cases since 2012 to present day (5)
- Clinical database (4D) notes for the above
- PACS (cardiac catheter and echocardiogram) and Angiographic Images
- Surgical Conference / MDT case discussion notes with rationale and decisions to list the case for surgery and the planned surgery
- Clinical Governance Committee Mortality Review meeting notes with Case presentations
- Discussions with lead clinicians
- Incident investigation reports and Coroners' inquest verdicts
- Theatre log book data

A standardised methodology will be used across all case reviews.

Report governance

The Review Team will sign off the report of the review before final submission to LTHT and NHS England

Family Experience Report

A thematic analysis of the experience, views and concerns of some of the parents whose children received care from Leeds Teaching Hospitals NHS Trust Children's Cardiac Services between 2009 - 2013.

"I would like to express my gratitude to the children, parents and families for the time they spent with me and the sincere and open way in which they have shared their stories."

**Professor Pat Cantrill
March 2014**

1. BACKGROUND

On 28 March 2013 a meeting was convened at Leeds Teaching Hospitals NHS Trust ("the Trust") with the Chair, Chief Executive and acting Medical Director of the Trust. The Care Quality Commission (CQC) and local commissioners were also in attendance. At this meeting a mortality data analysis was presented to the Trust. It showed the Trust to be a significant outlier with regards to mortality. In addition the Trust was informed that a number of families had expressed concerns to the CQC and NHS commissioners and to healthcare professionals in another children's cardiac unit.

In light of the concerns, the Trust agreed to temporarily suspend the service. NHS England convened a Quality Surveillance Group and two Risk Summit meetings during April 2013. Through this process it was agreed that NHS England would commission, on behalf of the Quality Surveillance Group, an independent investigation to collate and review the concerns being raised by families.

2. CONTEXT

Caring for children with congenital heart conditions is one of the most complex areas of modern medicine. About 3,700 operations take place each year in England. Leeds Teaching Hospitals NHS Trust's Paediatric Cardiology Surgery Unit undertakes between 350 - 400 surgical procedures each year. In addition as part of this service a large number of children attend outpatients both in Leeds and in surrounding local satellite hospital clinics. Patients are referred to the Leeds service by local paediatricians working as part of a network in Yorkshire and neighbouring counties.

3. AIMS

The overall aim of the work commissioned was to review the effectiveness of the support given by Leeds Teaching Hospitals NHS Trust (Leeds Trust) to parents and children receiving cardiac care who had approached NHS Commissioners and the Care Quality Commission with their concerns.

The terms of reference for this review are given in Appendix 1.

The report identifies aspects of both positive and negative experience as well as the views and concerns of those families who consented to take part. The findings have been grouped into themes relating to stages of the patient journey. From these, the report then identifies relevant actions to be considered by the Trust.

4. METHODOLOGY

During the summer of 2013 NHS England commissioned the services of Professor Pat Cantrill as an experienced independent service reviewer. Professor Pat Cantrill is a Registered Nurse and Health Visitor and was a senior civil servant at the Department of Health. Pat has led a number of high profile serious incident reviews. She has significant experience of undertaking and managing complex investigations. Professor Cantrill is a Visiting Professor at Sheffield Hallam University

The report collates the experiences of 16 children and their families.

NHS England contacted those families who had previously contacted the CQC and commissioners with concerns or complaints, informing them of the opportunity to take part in the review. In addition, NHS England contacted key patient support groups serving families and children with congenital cardiac conditions. These groups included:

- The Children's Heart Foundation
- The Downs Heart Group
- Little Heart Matters support group
- Leeds Children's Heart Surgery Fund
- Fragile Hearts group.

Each of the above groups were contacted directly and asked to consider sharing the NHS England letter of invitation to be part of the review with any families they felt may wish to take part. In this way the families contacted were self-selecting. The families were provided with the aims of the review and asked to consent in writing to participating.

Information was gathered by semi structured individual in depth interviews and unstructured observations.

The review presents a description of patient and parent experience from the perspective of the receiver of care. Patient medical records were not reviewed as part of this exercise.

The experiences, views and concerns of the children and families give rise to a number of issues and themes.

The report does not make direct reference by name to individual children or families. Direct quotes from parents are used throughout this report where appropriate. Where relevant the name of the child is included as part of the quote from the family.

Any names used are pseudonyms.

5. KEY FINDINGS

The report collates the experiences of 16 children and their families. The majority of the families' experiences of using the service relate to the time period 2009 to 2013. Some families have a history of more than 12 years contact with the Trust whilst for others it was less than one year. Six children who were originally patients at the Trust chose to have their care transferred to a different children's heart unit. In the case of six families interviewed as part of this report, their child had died following cardiac surgery at the Trust.

The findings from the review have been grouped under the headings of

- (i) Antenatal diagnosis and care
- (ii) Provision of child-centred and family-centred care
- (iii) End of life care
- (iv) Openness, transparency and candour
- (v) Responding to complaints and feedback

Detailed findings are as follows:

(i) Antenatal Diagnosis and Care

Most cases of children with congenital heart conditions occur in low risk pregnancies and are only detected by screening at the time of obstetric ultrasound scans. Most of the families involved in the review became aware of their child having heart abnormalities at a routine 20 week antenatal scan. In most cases this was at a local hospital, after which a referral was made for follow up care in Leeds.

Families felt that the counselling and support provided following the diagnosis of the congenital heart condition was inadequate, and there was a perception of little compassion or understanding.

"We had the scan and were asked to wait in this little room, for around 20mins which seemed to be like a lifetime. When the doctor and nurse came into the room to advise us what they had seen, we felt no empathy, sympathy or care. We felt like a piece of meat on a conveyer belt. It didn't seem like they were talking about our little girl, they were talking about a thing. They kept calling her the foetus. We were given the outcome and we asked if Elizabeth's heart condition was operable, and they replied no. They focused a lot on negative outcomes and didn't give us any positive. I kept asking if they could be wrong, and if there was any chance. All I got in response was if you decide not to terminate, we can scan you again at 28 weeks to see if there is any improvement" (Parent of Elizabeth)

"They did the scan and then I went into a room where there was a Doctor and a nurse. I was told my baby had half a heart. There was no compassion. I cried. The doctor said that the recommendation was to have a termination. I asked if there were other options and I was told I could go to full term and have the baby and then it would die or have the baby and then have surgery but that was not recommended. I was given a booklet and two days to make a decision. I was told not to look things up on the internet. I was sent to the antenatal clinic and waited from 2 o'clock until 5 o'clock. I was exhausted. My father went and asked for someone to see me. The staff had not been told about me. Then a Doctor rang me at home on the Friday for my decision. I said I did not want a termination. I was told it was the biggest mistake of my life." (Parent of Tom)

Most families felt that they were not given all of the information that they needed to make such a difficult decision about the future of their pregnancy and therefore their child. Some families were provided with a leaflet to read, some were told not to look on the internet for further information, and some were left waiting in a distressed state, or in rooms on their own, and in one case left in a corridor.

"We were told not to look up the condition or research online as it wouldn't do us any good. They left us in the room with the nurse for 20 minutes as I was still crying and a wreck" (Parent of Elizabeth)

Families felt pressurised to have a termination of pregnancy, and when they decided not to proceed with termination they felt they were treated with contempt.

"I was asked if I wanted a termination and I said no. The Doctor told me that I should consider things carefully as it was difficult to cope with a child in hospital" (Parent of Mark)

"After the scan we were taken into a room where we discussed the options that were available. Termination of my daughter's pregnancy was a subject spoken about greatly." (Parent of John)

Families felt that their individual circumstances or religious and moral beliefs were not adequately taken into consideration. A Muslim mother felt pressurised to have a termination although this was strongly against her own religious beliefs.

"I was referred to LHT by my local hospital as they were concerned about my 20 weeks scan. I was 21 years old and this was my first baby. They told me that the baby had a problem with its heart and would not live and that the best thing to do was to have a termination. They gave me a book and said think about it. I was devastated. I had another scan and was again told the best thing to do was to have a termination. They seemed against me

continuing with the pregnancy. As a Muslim I believe that abortion is wrong. They did not seem to understand." (Parent of Aziz)

Parents did not feel that information about their child's condition or family circumstances was used effectively to plan delivery of their baby. Some mothers asked to visit obstetric units close to the heart units that could provide the intervention required by their baby and were told that that was not possible. Some families expressed that they had to pressurise consultants to have their baby close to the preferred heart unit and in some cases have arranged this themselves.

"I was told that I would be admitted to hospital before the date my baby was due as I would have a Caesarean. I asked if we could develop a plan. I was told that I would stay in Leeds but the baby would go to Birmingham or London. I asked if I could see where my baby would go and was told it was not possible. They treated me like a number. I transferred my care and the care of my baby." (Parent of Tom)

Families had the perception of a lack of care planning for the delivery of their baby.

"I contacted the unit and the liaison nurse told me to come in at 8.30. Then I was told not to come in. Eventually a decision was made for me to go to the hospital on Sunday. I had to travel on the train on my own as there was no one to look after the children if my partner came with me. I had warned the midwives that I had very short labours and did not feel any pain. When I was in the 2nd stage of labour there was no neonatal team in the room and when his head was born I had to stop pushing and wait till they came." (Parent of Mark)

Many of the families felt that they should have been offered expert genetic counselling to enable them to make a decision about future pregnancies. In some instances the families needed a better understanding of the reasons why their child had developed a heart problem as part of a genetic condition.

"They told me that if I had another baby that it would have the same heart problem. I felt that I could not cope with another child with problems so I decided to be sterilised. I have now found out that wasn't right, that if I had another baby it would not have heart problems. I want another baby and I am trying to get the sterilisation reversed." (Mother of Susan)

As a result of these findings, the Trust is recommended to:

- **review the service it provides with respect to the environment, compassion, supporting information, counselling, and support offered to pregnant mothers whose children are diagnosed with congenital cardiac problems**

- review the care planning for delivery of babies with congenital cardiac problems
- review the availability and timeliness of genetic counselling services

(ii) Provision of child-centred and family-centred care

Families said they did not experience child-centred or family-centred care. Families did not feel as if they were kept fully informed of treatment options or changes in their child's condition, or that they were involved fully in care planning and decision making.

"From November to December I could see John becoming very ill. He was breathless, sleeping 90% of the day, constantly blue, sweaty and also vomiting frequently. We went to our local GP and also the local hospital sometimes twice a week, to get his SATS¹ checked as we were just not happy. We were also not happy there was no care plan in place for John. He was on the 'wait-and-see/as-and-when-required' path. Alarm bells starting ringing when a Consultant at our local hospital questioned why no care plan was in place when John was so poorly." (Parent of John)

Some families expressed a view that staff did little to get to know them as individuals or as a family and therefore the care and support they received did not fully reflect their child's or their family's needs.

"I was made to feel that I was making things up when I said that Becky kept falling asleep and had difficulty breathing." (Parent of Becky)

"Staff did not listen. On the day of her test we asked that Pauline might use a bike as she had difficulty walking. We were told that was not possible. Pauline could not complete the test. We were not taken seriously and Pauline was upset. They did not listen to her and to us." (Parent of Pauline)

The families did not feel that there was a systematic coordinated plan of care that guided the children, family or professionals through the child's care journey. They felt this would have allowed them to have a better understanding of the care their child needed, the best place to deliver it and the role of professionals. They wanted to have a greater involvement in making decisions about their child's care. They also believed it would have helped the whole range of services their child needed access to collaborate closely to ensure that their child received consistent and co-ordinated support, both in the Trust and across the Local Network Centres, primary care and community services.

¹ Oxygen saturation is a clinical measurement that determines what percentage of a patient's red blood cells are saturated with oxygen after passing through the lungs. It is a result that reflects not only how well a patient's lungs are working but also how effectively oxygen is being delivered to all parts of the body. In a healthy child breathing room air, the oxygen saturation levels will be between 96 and 98 percent. In some children with complex (cyanotic) heart conditions, saturation levels of 70-90% may be viewed as the norm.

"They did not seem to have a plan to manage the symptoms of Tim's heart failure. There was no plan of care that we could see, particularly to ensure there was continuity of care between Leeds and our local hospital. We were made to feel that we were exaggerating the problems he was having. That Tim's problems were fictitious. We struggled to get information. They don't seem to want to learn from mistakes. There was no plan of care. The staff seemed to work in a reactive way on a day to day basis." (Parent of Tim)

It is not surgically possible for many children with complex congenital heart disease to have their heart returned to the normal structure and therefore the operations performed are commonly defined as 'palliative' procedures. This means the care given or the operation done is intended to improve a child's quality of life by dealing with the symptoms of the condition but it is not actually a cure for the underlying problem. In the later stages of the child's life, palliative care which is care for the dying may need to be given by specialised units such as children's hospices. Some families involved in this review said they were not aware that their child's condition was being managed by care or an operation that was palliative and not curative. For some families the fact that the decision had been made not to pursue surgical intervention was a complete surprise.

One family was told to contact the Children's Hospice for support only to find that the hospice knew nothing about them and that their child did not qualify for the service. In one case the hospice contacted the mother of a child because a referral had been made by the Trust. The mother did not know that the hospital had contacted the hospice and was distressed that this had not been discussed with her.

"After Tim's stroke there was a lack of compassion for him and for us. They did not recognise how hard Tim had worked to get better. We were refused access to the children's hospice. You felt you were on your own. There was no one to talk to about your concerns or to ask for advice." (Parent of Tim)

Families reported not being aware of a key health professional coordinating their child's care or the involvement of the multidisciplinary team. Families felt they did not have an identified lead person who they could contact for advice and support.

Some parents expressed their concerns that delays in treatment and investigations resulted in a worsening of their child's condition. In some instances these delays were said to be years or months. Some families felt that the surgeons waited for their children to deteriorate before operating and in some cases that the surgeons appeared nervous to undertake the procedure and therefore delayed it. Families believe that this has resulted in children's condition worsening to a point where it made intervention more difficult and life threatening. Some have been told by another heart unit that earlier intervention could have taken place and this has added to a lack of confidence in the Leeds Trusts' ability to make the right decisions for their child. Some waited for the

hospital to contact them about their child's surgery only to find that the child had been removed from the waiting list without them being informed.

"We were waiting to receive a letter for Shona to go into hospital for her heart surgery. I was a nervous wreck. She started to deteriorate. I contacted the hospital. They made me feel as though it was me and that I was being over protective and that I would just have to wait. I said that we needed to see someone and eventually we saw the cardiologist. The scan did not show anything different. We had waited for 3 years for her surgery but when we saw the Doctor she told us that Shona was inoperable and that she was not on the waiting list. We were confused and my husband was upset and started to ask questions. We asked for a second opinion. She said we would only be told the same things. We were told no one else could help. The Doctor walked out." (Parent of Shona)

Families felt that investigations such as catheter tests, brain scans or up to date cardiac scans did not appear to have taken place, and that some operations were done based on scans taken two years prior to surgery. In some cases it was felt that a referral to the paediatric intensive care unit was delayed by a lack of staff. There were also concerns about surgery being undertaken when children had infections.

With regard to getting second opinion or specialist advice, families perceived a delay in doctors liaising with specialists from within the Trust or doctors in other heart units. The families believe that Leeds Trust is more inward looking and this has impacted on continuity of care for children and their families.

Families reported distress caused by the reluctance they perceived of Leeds doctors to refer their children to other heart units. Families who asked for transfer of care to another unit said they were advised that the other unit did not offer the care their child needed. Families experienced difficulties getting the Trust to transfer documentation about their child's care and in some instances important documentation such as theatre operation notes were missing. Families felt that political and financial issues got in the way of children getting the care they needed. Some families believe that as a result of requesting a transfer to another hospital they have been accused of harming their children and in some cases they have been referred to social services which added additional stress for the families.

The families believed that the Local Network Centres were not kept fully informed. Families said that doctors at the Local Network Centres informed them of this as well as expressing concerns to them about the delays in and quality of care provided by the Trust.

On the Trust's website it identifies that families are given a green and white information folder which supports the shared care between the Trust and the

Local Network Centres. Families interviewed were not aware that this existed and could not recall being given a copy.

Local primary and community services in most instances were not informed about the care required by children. There was little evidence in the GP letters seen that information was being provided about the care of the child to assist the palliative care of the child and support of the family. In the case of John for instance local services were not informed about his death resulting in midwives having to be informed by the mother about the death of her child. The mother feels that she did not receive the appropriate services or bereavement care.

Access to a clinical psychologist or bereavement counselling was felt to be an important requirement; however families felt this was not adequately provided for them.

"After Tim died the shutters seemed to come down. There should be counselling provided for parents who have lost their child." (Parent of Tim)

The families identified that not all of the care they received was a negative experience. Some of the families whose child had been attending cardiology services in the Trust for a number of years said at first the care they received was good. They felt their child received care from staff that were compassionate, caring and competent but gradually that had changed and it had become more difficult to get information and care had deteriorated.

Some families state they have experienced a lack of a child and family focused approach by some nursing staff, including aspects of care delivered by the specialist children's cardiac nurses. The families identified the importance of this role and that the quality of compassion, care and information sharing given by these nurses was variable.

"We needed more support from the specialist cardiac nurse. It was difficult to contact them particularly when there had been problems. Our experience at the other hospital has been totally different. They ring you in between appointments to see how things are going and support you during outpatient appointments and when Sophie has been in hospital they have been there to answer questions and help. They make you feel cared about and for." (Parent of Sophie)

Some families believed that aspects of nursing care were poor and raised concerns about hand hygiene by the nurses, children being left unwashed and in pain, and children not being fed if families were not there at mealtimes.

"I didn't find the nurses friendly. Mark had a yellow discharge running down his face from his eye they didn't clean it. I cleaned it. He sounded chesty and I mentioned it to the nurse but she didn't say much. He went for his operation when he was a week old in the morning. I went down with him. Mark was one of the most critical babies on there and one nurse that never cared for him

before wasn't happy that the monitor was going off all the time, and ended up silencing the machine. One nurse didn't know how to do his dialysis and had to be shown how to do it. One nurse didn't use gloves to break his dialysis fluid to mix it, because one nurse couldn't break them, so another nurse did. The cleaner didn't clean under his cot only around there was mess under his cot and they left a plastic cap in his cot." (Parent of Mark)

Many of the parents were distressed by the lack of distraction when their children had investigations such as blood tests. This resulted in future anxiety for the child and parents.

"When they took blood it was awful. They would hold her down. They had 12 attempts to get blood by four different doctors. She was so distressed and so were we. At the other hospital it could not have been more different. They have a distraction room and they play videos whilst they are taking blood. She can cope with it now." (Parent of Sally)

Some of the families found it difficult to take a break when their child was seriously ill and needed constant observation. They said they preferred not to leave their child as they could not be confident that a nurse would stay with the child. Families were grateful that accommodation was provided to enable them to get some rest, however a number found that if they did have a break particularly during the night they were not contacted by the staff when there had been a change in condition of their child. This led to a loss of confidence and a subsequent reluctance to leave the ward. Some also found the facilities were dirty and therefore not comfortable to stay in.

"The nurses kept forgetting to bring Sally food. The day after her operation we told a nurse we were going for a break and when we came back Sally was covered in vomit and blood and nurses had not been to see her. She should have had someone with her. We aren't leave her after that." (Parent of Sally)

As a result of these findings, the Trust is recommended to:

- Review its service to ensure the care delivered is child and family-centred, with a clear care plan for each child, made available to families and all relevant professionals
- Review arrangements for a lead professional or key worker who parents can contact as and when needed
- Review arrangements for communicating a coordinated care pathway across the network of satellite hospital services.
- Review the role of the Children's Cardiac Specialist Nurse to be sure that this role provides the necessary support to families when the child attends the unit or is in hospital and importantly when the child is at home.
- Ensure all nursing staff provide the same high quality compassionate care

- Review the processes for keeping parents informed at all stages of care, in relation to the treatments being provided, changes in their child's condition and for providing clarity about palliative treatments
- Review the provision of information, counselling and support services
- Review arrangements for giving parents a break from the ward and the quality of the accommodation provided.
- Review arrangements for liaison with and referral to other heart units

(iii) End of Life Care

The death of a child is a time no parent ever forgets, and what happens in the hospital while a child is dying is likely to have lasting repercussions.

*"That night after his surgery they could not stop the bleeding. The Chaplain baptised him. It was a very foggy night and he died at midnight. No one offered any comfort. No one asked how we were getting home. The nurse at Coroner's court said they gave parents bereavements packs but we were not given one. She said it was ticked off on the list but we were not given one."
(Parent of Ryan)*

The families felt that the delivery of bad news about the terminal condition of their child was not handled well. In some cases the doctors broke bad news then rushed away. In most cases, the child was on ventilator support and the families had the difficult decision to make whether or not to stop this intervention. Those families affected felt a lack of compassion at this time. Some families whose child died said that the death of their child was a shock because although they knew that all surgery has a risk they had been reassured that the procedure had gone well. This they say was followed by a sudden deterioration in their child's condition with further emergency surgical intervention required. The families believe that they were not given complete information about what led to the deterioration in the condition of their child.

"Mark took a turn for the worse. They soon ushered me into a room by myself as they didn't want other parents seeing me cry... No one came to see if I was ok." (Parent of Mark)

"The Doctor came out and looked at Mark's eyes, she looked at them twice and then phoned the Consultant. She got back to me and said she was talking to the Consultant. She said can we have a word she took me in a room. I said to her it's not good news is it and she said it's not and she said Mark was dying. She asked if I wanted to hold him. She said you have to let him go and that they would be turning his ventilator off. They got me a chair and placed him in my arms. You could see his skin was pale and white and not long after they took his tube out he went instantly in my arms." (Parent of Mark)

*"Being a Muslim there are certain things we do when someone is dying and I needed my father to pray for my baby but he was not allowed to see the baby. They did not understand our religious beliefs and requirements."
(Parent of Aziz)*

Families recognised that there was a need to discuss their child's options for organ and tissue donation but they felt that the timing lacked sensitivity.

"I was told the MRI had shown that Annie had horrific brain injury. I was then taken into a room to speak to a neurologist, who informed me that Annie's injury to her brain was going to cause Annie to die. He explained to me in what can only be described as a cruel and insensitive manner that Annie's brain was squashing down into her spinal cord using hand and facial gestures which I think would only be appropriate in a student's lecture not to a grieving parent. ... He then told me to turn her ventilator off. Annie's Dad and I declined. He then went on to ask about organ donation, which I said I was happy to do but Annie's Dad did not want this. The neurologist asked her Dad why, as she wouldn't need them. We thought this comment was unnecessary. The neurologist then said he was turning her morphine off and she would deteriorate to the point where Annie would pass herself.

I was then told by a different neurologist to be prepared if Annie was to pull through this, she would be treated at the hospital for a very long time. I also recall the first neurologist coming to Annie's bedside and asking me if Annie's Dad was on Annie's birth certificate or if we were married, implying for me to overrule her Dad's decision not to donate the organs and to not resuscitate. I am not entirely sure at what point he came and said this to me but I know it was only a short period of time between being given some hope and this neurologist taking it away". (Parent of Annie)

Some families whose child had died felt they were not treated with compassion; they felt that they were an embarrassment and that the staff wanted them to leave as quickly as possible after their child had died. They were not provided with a room to sit quietly. No one told them what the process was. They felt lost. The practical issues of how they were getting home, in some instances during the early hours of the morning, were never raised or help offered. For one family the death of their child coincided with film cameras being on the unit filming the staff's reaction to a court decision and they found the whole experience very distressing as their needs were lost in the excitement of staff and campaigners.

"We were given no support by the staff after Annie died. We were given a leaflet. Nobody asked how we were getting home in the early hours of the morning." (Parent of Annie)

One family attended the Chapel of Rest to view their child but were given the wrong time to arrive and had to wait to be escorted by a porter who left them sitting inside the Chapel of Rest. The grandfather had to find someone to ask what they should do. This has added to their grief.

"David decided that he wanted to keep a record of his life and started to write all his experiences, thoughts and feelings in a book. He wrote about his heart condition and the care he received. It had his thought and feelings in it. It was one of his ways of coping by writing things down. After he died we went to collect his things and the book was missing. It was really important to us. It was like losing another part of him. We asked the staff to find it. They told us they could not find it. They didn't seem bothered. They didn't seem to realise what it meant to us. We had been going to Leeds for 10 years and no one has rung to see how we are." (Parent of David)

Families affected by the death of their child reported not being offered contact with a bereavement counsellor or clinical psychologist experienced in the care of paediatric cardiac patients to support them.

As a result of these findings, the Trust is recommended to

- **Review arrangements for end of life care to ensure care is compassionate and child and family centred at all times**
- **Review the ways in which bad news is delivered**
- **Review the ways of holding discussions about tissue and organ donation**
- **Review availability of a bereavement counsellor or clinical psychologist experienced in the care of paediatric cardiac patients**

(iv) Openness, Transparency and Candour

Families expressed their concerns about the lack of communication particularly when the outcomes of care were not as planned. Most families believed that when incidents occurred during surgery the facts were not shared with them by surgeons and others. This has resulted in an increased concern for them believing something had gone wrong and then that it had been covered up. They felt as though they have had to fight to get information.

"They told us Maria had a complex heart condition that they had not seen before. Why didn't they contact other people for advice? After her first operation Maria had pneumonia but no one told us for a week." (Parent of Maria)

"They removed part of my baby's heart at the first operation but no one told me I only found out after a second operation at another hospital." (Parent of Gemma)

Families wanted to be able to get reliable information from the Trust website. Like many users of health care services, families could be overwhelmed by what is available on the internet and they were in need of highly credible information and guidance from professionals. The families said that they found the website

for families of children with congenital heart problems provided by Leeds Trust to be dated and lacking useful information.

Some of the families reported other health professionals informing them that incidents had occurred during surgery which resulted in emergency intervention, but that they had not been informed of this by the surgeon who undertook the operation. They reported receiving conflicting messages at times. One family was told by a paediatrician that their child could not be operated on because of the complexity of his heart condition. A short time afterwards they were contacted by the hospital and asked to bring him for surgery. Subsequently the child died. The parents recalled asking why the surgery had gone ahead and said the paediatrician described being out-voted at the case meeting and that the surgery should not have happened.

*"Nurses were afraid to speak out."
(Parent of David)*

As a result of these findings, the Trust is recommended to

- **Review the services to make sure discussions with parents about errors in care are held openly and with candour.**
- **Ensure parents receive full and complete information about their child's care at all times**
- **Review the content of the website to assess if it meets the information needs of parents and children**
- **Review its whistle-blowing policy and practice and ensure that staff recognise their responsibility to maintain the safety of children and their families.**

(v) Responding to Complaints and Feedback

Families who complained to the Trust felt that the response they received to their complaint lacked understanding and lacked an appreciation of the complexity of the challenge they experienced. Families felt that they were misunderstood and misrepresented and their complaints left unresolved. The families said that they have been made to feel that the children and the families are the problem. The issues raised by the families were either not answered at all or a defensive response was given which failed to answer the families' concerns.

"The response to my complaints seemed to blame me and that I had got things wrong rather than answering my questions. The response to our complaint was insulting. They did not answer our questions." (Parent of Annie)

As a result of these findings, the Trust is recommended to

- **Ensure complaints are handled and responded to in a way that adheres to best practice, sensitively, sharing all possible information and optimising the possibility for local resolution and relief of distress.**

6. CONCLUSION

Those families who wished their experiences views and concerns to be heard have been listened to. Their stories were all heartfelt, moving and sincere. All the families were saddened to find themselves in a position where they had lost confidence in the care provided for their children and for them as a family. They want the services for children with congenital heart conditions both nationally and locally to learn from their experience. They want services for children and their families to improve.

The experiences, views and concerns identified by the families have been used to establish a number of recommendations for NHS England, Leeds Teaching Hospitals NHS Trust and other heart units to assess the quality of services provided for children with congenital heart conditions and families.

It is likely that there will be other families with different stories about their experiences of children's heart services in Leeds, including some with completely positive stories. However this must not be allowed to stand in the way of hearing and acting upon the stories that underpin this report. It is imperative that our focus remains on improving health outcomes for children with congenital heart abnormalities and their families.

We have learned throughout 2013 as a result of the Francis report of the great importance and value of listening to patients, their carers, and their families. This report is yet another opportunity to do so.

APPENDIX 1

Review Terms of Reference

The overall aim of the work commissioned is to review the effectiveness of the support given by Leeds Teaching Hospitals NHS Trust (Leeds Trust) to parents and children receiving cardiac care who approached NHS England and the Care Quality Commission. To listen to parents of children who have used services at LTHT for children needing cardiac care to identify areas that have provided a positive and negative experience.

Key issues will be established to inform the lessons that need to be learned and as a result future changes to services.

The work will involve:

- Reviewing written information already obtained from parents and from other key individuals.
- Undertaking one to one or group interviews, telephone conversation or a listening event with parents to identify key issues. The method used will be based on individual parental preference.
- Reviewing and analysing information gained from listening to parents to identify issues and patterns associated with the support that parents and children have received.

It is anticipated that as a result of this work that there will be:

A report which identifies key issues and patterns related to parental concerns. This will be used to inform future changes to services and to identify areas of further investigation and/or development.