APPENDIX A

University Hospitals Bristol NHS
NHS Foundation Trust

Report to meeting in common of the Bristol People Scrutiny Commission and the South Gloucestershire Health Scrutiny Commission, 12 August 2016

INDEPENDENT REVIEW OF CHILDREN'S CARDIAC SERVICES IN BRISTOL

and

CARE QUALITY COMMISSION CASE NOTE REVIEW OF CARDIAC SURGICAL SERVICES AT BRISTOL ROYAL HOSPITAL FOR CHILDREN

1. INTRODUCTION

This paper is provided to support a specially convened meeting in common of the Bristol People Scrutiny Commission and the South Gloucestershire Health Scrutiny Commission on 12 August 2016.

It sets out the context for the Independent Review of Children's Cardiac Services in Bristol and the Trust's response to the two independent reports published on 30 June 2016:

- *The Report of the Independent Review of Children's Cardiac Services in Bristol*, Eleanor Grey QC and Professor Sir Ian Kennedy, June 2016;

- *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*, Care Quality Commission, 23 June 2016.

2. BACKGROUND TO THE REVIEWS

Child deaths in 2012

Concerns were raised in 2012 by two families about the deaths of their children in March and April of that year, following cardiac surgery at the Bristol Royal Hospital for Children.

CQC unannounced inspections

The Trust had responded to formal complaints from these families and sought to address their concerns but they were not satisfied with our explanations and contacted the Care Quality Commission (CQC). This prompted 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 us a warning notice requiring improvement.

An unannounced follow-up inspection by the CQC in November 2012 reported improvements in nurse staffing, with adequate levels of suitably trained staff on ward 32 and high dependency provision in place on the paediatric intensive care unit.

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, which remains part of our provision for sick children.

Independent review

However, some of the families for whom we had provided care continued to voice concern. In February 2014, the Medical Director of NHS England commissioned an independent review of the cardiac service at the Bristol Royal Hospital for Children, in response to the continuing concerns of families, including those whose children had died. NHS England worked with the families to develop and publish terms of reference for the review and asked Eleanor Grey QC to lead it, with Sir Ian Kennedy acting as an advisor.

Care Quality Commission review

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 and to conduct a clinical case note review, on a random sample of notes, to assess the care provided by the service. The purpose of the review was to provide an assessment of current practice at the hospital. The review focused on surgical interventions undertaken in the three-year period between January 2012 and December 2014.

The Independent Review panel led by Eleanor Grey QC was able to study the findings of the CQC's work, prior to finalising its own report.

The reports of the Independent Review and the CQC expert review were published on 30 June 2016.

Care Quality Commission comprehensive inspection

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

National Institute for Cardiovascular Outcomes Research report

In April 2016, the National Institute for Cardiovascular Outcomes Research reported that the 30-day survival for all heart surgery procedures at Bristol was comparable

with all 14 children's specialist cardiac centres during the three-year period 2012 to 2015.

National Coronary Heart Disease Review

In 2015, NHS England published new commissioning standards for specialist congenital heart disease services, following extensive consultation with patients and their families, clinicians and other experts. Since then, hospital trusts providing these services have been asked to assess themselves against the standards, which came into effect from April 2016, and to report back on their plans to meet them within the set time-frames.

As a result of these assessments, and following further verification with providers, on 8 July 2016, NHS England announced how it intends – subject to necessary engagement and service change processes – to take action to ensure all providers comply with the set standards. This included NHS England's announcement of its intention to support and monitor progress at University Hospitals Bristol (and a number of other recognised specialist surgical centres at major teaching Trusts) to assist us in our plans to fully meet the new commissioning standards which, as stated above, came in to effect in April of this year.

3. FINDINGS OF THE INDEPENDENT REVIEW AND CQC CASE-NOTE REVIEW

The full reports of both the Independent Review and the CQC case-note review were published on the Trust website on 30 June 2016 and are attached as **Appendix Ai** and **Appendix Aii** respectively.

Detailed conclusions and related recommendations are set out in each chapter of the Independent Review Report and its executive summary, and in the body of the CQC Clinical Case Note Review Report.

The extracts below are drawn respectively from the Independent Review Report (the Executive Summary and Chapter 17, 'Concluding Remarks and Recommendations') and the 'Conclusions' section of the CQC Report. They are reproduced faithfully here in their entirety and represent the published conclusions of each review.

Independent Review conclusions:

The Review reached the firm conclusion that there was no evidence to suggest that there were failures in care and treatment of the nature that were identified in the Bristol Public Inquiry of 1998-2001. The outcomes of care at the Children's Hospital were broadly comparable with those of other centres caring for children with congenital heart disease. There was evidence that children and families were well-looked after and were satisfied with the care their children received. There was, however, also evidence that, on a number of occasions, the care was less good and that parents were let down. The principal focus of the Review was on Ward 32 where children were cared for. It was clear that, particularly prior to the CQC's inspection in 2012, the nursing staff were regularly under pressure, both in terms of the numbers available and the range of skills needed. This led on occasions to less than good care for children and poor communication with parents and families.

The Review also reached the conclusion that, on occasions, the senior managers of the Hospital failed adequately to understand and respond effectively to the concerns of parents and adopted an unnecessarily defensive position in the face of the CQC's observations. This led to a deeply regrettable breakdown in communication which culminated in the commissioning of this Review.
…

We have noted what we consider to have been weaknesses in the response to evidence of risks on Ward 32, prior to the CQC inspection of September 2012, as well as strains on the capacity of outpatient clinics and the PICU [Paediatric Intensive Care Unit].

Detailed review of individual families' concerns suggested that there were some flaws in the management of investigations, such as RCAs [root cause analyses] and CDRs [child death reviews], but viewed overall, we accept that these processes were reasonably thorough, and candid. We did not see evidence of attempts to mislead or to avoid confronting areas of weakness. The investigations formed the basis of much of the work set out in the action plan which followed the CQC inspection. In the Review's judgment, there had been substantial learning, within cardiac services, from the criticisms which had been voiced and the findings of the Trust's own reviews and investigations.

The process of investigating a number of complex complaints or concerns did not succeed in maintaining, or rebuilding, trust between a number of families and the UHB and its staff…

CQC expert case review 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.

4. TRUST RESPONSE

We fully accept the findings of both these reports and welcome their publication as a way to learn from mistakes.

We are deeply sorry for the things we got wrong - for when our care fell below acceptable standards, for not supporting some families as well as we could have and for not always learning adequately from our mistakes. This undoubtedly added to the distress of these families at an already very upsetting time for them. We did not get it right for them, and we have apologised to the families unreservedly, on behalf of everyone at the Trust.

We are pleased the review found our outcomes were comparable with other hospitals caring for children with heart conditions, and that there was evidence that children and families were well-looked after and satisfied with their care, but we want to get our care right for everyone, every time, especially so when it involves children.

As the reports acknowledge, we have already acted to improve the care and support children and their families receive and there are areas where the investigation teams saw examples of good practice. However, we know there are improvements still to be made and will act with determination and pace to deliver on the recommendations within the reports.

Parents have already played an important role in bringing about significant changes and in improving the care we provide. This includes the way we communicate with families.

In formulating our plans to deliver the recommendations of these reports, we aim to make a partnership with parents the fundamental building block of our approach.

5. COMMUNICATION WITH THE FAMILIES

We do not know the identity of all the families who contributed to the Independent Review. We therefore posted an open letter on our website, repeating our apology for the things we got wrong, acknowledging the role played by parents in bringing about significant improvements to care and inviting contact from any of these families who wished to discuss their own child's care or to register an interest in working more closely with us in future.

The letter also noted that a number of families gave the Independent Review panel permission to share with us the reports of their individual expert case-note reviews. The Trust has been reviewing these reports to inform a personal response to each family.

A further open letter from the Clinical Chair for Women's and Children's Services to families currently under the care of the service invited any parents who have questions or concerns about their child's care in the light of the Independent Review to contact us. It also signposted a number of other sources of advice and information, such as support groups and websites.

6. ACTION IN RESPONSE

As described above, the Trust took immediate action following the CQC inspection in 2012 to make a range of improvements, including but not limited to the creation of a dedicated paediatric cardiac high dependency unit.

Chapter 14 of the Independent Review report recognises that "significant changes were made in the delivery of care on Ward 32 and in cardiac services more generally, in the wake of the CQC's inspection of September 2012" and that there has been "substantial learning, within cardiac services, from the criticisms which had been voiced and the findings of the Trust's own reviews and investigations".

The Review specifically highlights a number of important improvements which it had noted:

- the process of obtaining consent;
- arrangements to support the Joint Cardiac Conference;
- measures to improve team-building and develop leadership;
- introduction of a new Paediatric Early Warning Score system and new Paediatric 'Core Care Plans';
- family involvement in the development of a new protocol empowering parents to 'escalate' concerns about their child's clinical condition or care;
- improvements in multi-disciplinary team communication and participation in ward rounds;
- creation of the new high dependency unit and associated cover arrangements;
- an investment of £1.6 million to increase the number of children's nurses to levels which support one nurse to three patients receiving care on the ward during the day and one to four at night, with one nurse to two patients in the Cardiac High Dependency Unit;
- investment in a dedicated cardiac educator for the paediatric intensive care unit and Ward 32 to support staff in the development of clinical skills.

Notwithstanding the substantial progress already made, the Trust fully accepts that more needs to be done to meet the comprehensive and far-reaching recommendations of both the Independent Review and the CQC's case-note review.

Appendix Aiii sets out the Trust's analysis of the organisation responsible for delivery of each recommendation and, where that organisation is the Trust itself, the designated owner, as well as our initial assessment of the expected time to complete key first steps in each case.

Our Chief Nurse is the Board sponsor of the work programme to address the recommendations from these reports and implement our action plan for improvements. The role of the Chief Nurse as Board representative of Children's Services was strengthened in consultation with our Women and Children's Services Division in April 2015 and we will keep this role and the extent of responsibilities it should cover under review in line with Recommendation 22 from the Independent Review.

A dedicated project manager has been appointed to co-ordinate and support action planning, delivery, and progress reporting internally and to external stakeholders as required.

7. PROGRAMME MANAGEMENT

A model of governance for the work programme to make decisions, deliver and report on all the recommendations relevant to the Trust was agreed by the Trust Board on 28 July 2016 as follows:

- A **steering group**, chaired by the Chief Nurse, and via her linked to the Executive Team and the Trust Board, will be responsible for oversight and co-ordination of the work programme and will include - at a minimum – the divisional Clinical Chair and relevant Clinical Director, and representatives of the children's cardiac service, the South West and South Wales Congenital Heart Network and parent support groups.
- In keeping with the Trust's commitment to strengthen its partnership with families, a **parent reference group** will be established to support the work of and advise the Steering Group. We will ask the parent reference group to provide assurance that plans to meet the recommendations take proper account of the needs and perspectives of families.
- **Working groups**, reporting to the steering group, will be established as needed to take discrete areas of the work programme forward, including but not limited to a review of the consent policy and process (Independent Review recommendations 13, 14, 16 and 17 and CQC recommendation 1) and subsequent actions, and a review of incident and complaints investigation processes and subsequent actions (Independent Review recommendations 26 to 30). The working groups will include appropriate front-line staff within the children's cardiac service and the wider Children's Hospital.

Figure 1 shows the outline governance structure. External reporting arrangements will be agreed with appropriate regulatory, commissioning and scrutiny authorities.

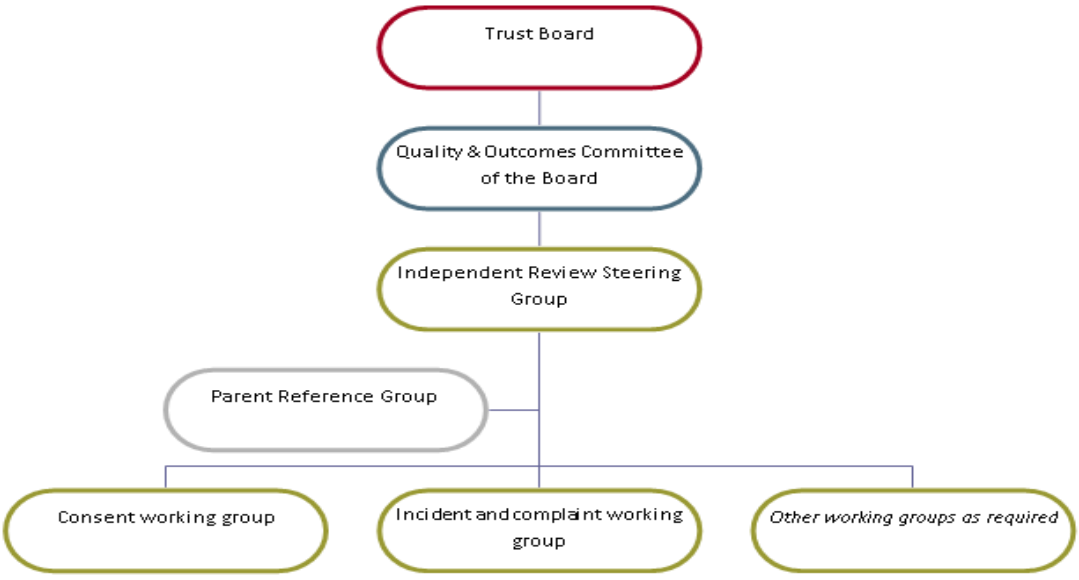

Figure 1. Proposed governance model.

8. CONCLUSIONS AND RECOMMENDATIONS

The Trust would like to take this opportunity to:

- Reiterate to the affected families how sorry we are for the things we got wrong – for when our care fell below acceptable standards, for not supporting some families as well as we could have and for not always learning adequately from our mistakes, adding to their distress at an already very upsetting time for them.
- Re-affirm our full acceptance of the recommendations of these reports.
- Acknowledge publicly the role which parents have played in bringing about significant changes in practice and in improving the provision of care in the paediatric cardiac service (Independent Review recommendation 31). We thank those who have supported the reviews, given feedback, and already worked with us to make improvements. We support this as an ongoing approach.

Councillors are asked to:

- Seek further information and assurance about the progress of the action plan.
- Agree that they will receive regular reports from the Trust of progress against the recommendations from both reviews until further notice.
- Confirm that they intend to visit the Bristol Royal Hospital for Children later in the year to see the new facilities for themselves.
- Identify any further information which would assist them in their scrutiny function.

Robert Woolley
Chief Executive
3 August 2016