

Report to meeting in common of the Bristol People Scrutiny Commission and the South Gloucestershire Health Scrutiny Commission, 27 February 2017

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

INTRODUCTION

This paper is provided to support a meeting in common of the Bristol People Scrutiny Commission and the South Gloucestershire Health Scrutiny Commission on 27 February 2017.

The report provides an update to Council Members on the progress of the programme plan to deliver the recommendations for University Hospitals Bristol NHS Foundation Trust and South West Congenital Heart Network as set out in;

- *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.

For the background to the reviews see Appendix 1.

PROGRAMME MANAGEMENT

Independent Cardiac Review Steering Group

The steering group has met monthly since September 2016. It has had representation from NHS England and Welsh Commissioning since its inception and family representatives since December 2016. It has three working groups reporting to it:

- Women's and Children's Delivery Group
- Incident and Complaints Delivery Group
- Consent Delivery Group

These groups have clear terms of reference and are responsible for delivery of agreed actions that will ensure that the recommendations that relate to their areas of practice/service delivery are completed within the agreed timescales. There are detailed action plans for each group (See Appendix 2). Good progress is being made with delivering the actions. There a number of actions that are rated amber on the of the action plan. The key reason for this is the rigor of the assurance process prior to recommending actions for closure. The plan shows that all actions to deliver the

recommendations of the Independent Cardiac Review will be completed by 30 June 2017.

Reporting is a month in arrears to allow for validation and sign off of action plans by the relevant steering groups each month, before submission to the Trust Board.

ASSURANCE FRAMEWORK

Parent representatives have been appointed to act as the parent voice on the steering group (see Roles and Responsibility document, Appendix 3). A Cardiac Families Reference Group has been set up to act as the voice of the family and provide an objective “sounding board” for the paediatric cardiac service (Terms of Reference, Appendix 4).

- Four parent representatives attended the Steering Group meeting on 9 January and 7 February 2017.
- The Virtual Parents Reference Group has been used to review evidence as part of the assurance process prior to recommending actions for closure.
- There are fifteen projects in the action plans that have had, or will have, family involvement in the associated service developments and sign off of these actions as complete.
- A young person’s involvement consultation has commenced to explore how these service users would like to get involved and feedback on where and how the Trust could further develop/improve service provision. The initial feedback indicated there are a range of ways young people would like to be involved in the Independent Review and ongoing service improvement work.

CONCLUSIONS

The Trust is committed to truly learn from the Independent Review and not treat the recommendations as a ‘check list’ of actions.

Underpinning the delivery of the recommendations is a commitment to learning and change, and an understanding that when we listen to the views and experiences of families and young people we can provide better quality services in a way that meets their needs.

NEXT STEPS

- Completion of actions to deliver all recommendations by June 2017.
- To provide for each completed recommendation a robust audit trail of supporting documentation and evidence.
- To move any service improvement actions identified through the review but not required to be completed to deliver the recommendations into an appropriate pre-existing working group.
- To ensure residual risk(s) are recorded in accordance with the risk policy.
- To continue to involve families through the forums set up to support the delivery and sign off of the actions/recommendations in the Independent

Cardiac Review in the co-design of services within the Bristol Royal Children's Hospital.

Carolyn Mills Chief Nurse
15 February 2017

APPENDIX 1

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.

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 provided to members.

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.

PROGRESS REPORT AGAINST UH BRISTOL RECOMMENDATIONS FROM THE INDEPENDENT REVIEW OF CHILDREN'S CARDIAC SERVICES – November 2016
1. Women's and Children's Delivery Group Action Plan, Senior Responsible Office: Ian Barrington, Divisional Director

Progress overview							Detailed actions				
No.	Recommendation	Lead Officer	Completion date	Status	Delivery Risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
2	That the Trust should review the adequacy of staffing to support NCHDA's audit and collection of data.	Deputy Divisional Director	Apr '17	Blue- on target	None		Review of staffing	Assistant General Manager for Paediatric Cardiac Services	Sept '17	Green-complete	Staffing review report
							Results and recommendations reported at Women's and Children's Delivery Group in Sept. '16.	Assistant General Manager for Paediatric Cardiac Services	Sept '17	Green-complete	Women's and Children's Delivery Group Agenda and minutes 20.09.16
							Requirement for additional staff will feed into business round 2016-17	Assistant General Manager for Paediatric Cardiac Services	Apr' 17	Blue- on target	Expression of interest form and Women's and Children's Operating Plan
3	That the Trust should review the information given to families at the point of diagnosis (whether antenatal or post-natal), to ensure that it covers not only diagnosis but also the proposed pathway of care. Attention	Specialist Clinical Psychologist	Apr '17	Blue- on target			Information given to families at the point of diagnosis reviewed by the clinical team and the cardiac families – remaining information for Catheter Procedures and Discharge leaflet. Website and leaflets updated to reflect improvements	Clinical Team & Cardiac Families	Jan' 16	Green-complete	Revised patient information leaflets
							Links to access relevant information to be added to the bottom of clinic letters for patients.	Specialist Clinical Psychologist	Dec '16	Blue- on target	Clinic letter with links
							Review and amendment of Catheter and Discharge leaflet	Cardiac CNS team	Feb' 17	Blue- on target	Revised Catheter and Discharge leaflet

Progress overview							Detailed actions				
No.	Recommendation	Lead Officer	Completion date	Status	Delivery Risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
	should be paid to the means by which such information is conveyed, and the use of internet and electronic resources to supplement leaflets and letters.						Enhance existing information with a visual diagram displaying pathways of care (FI).	Specialist Clinical Psychologist	Apr '17	Blue-on target	Pathway of Care accessible visual
Website proposal to be written for new Children's website including cardiac information similar to Evelina to improve accessibility of our information. <i>This will be additional and not essential for delivery of the recommendation (FI).</i>							LIAISE Team Manager and Specialist Clinical Psychologist	tbc	Started		
Smart phone App proposal to be written for Cardiac Services to enable patient/families to access information electronically (FI). <i>This will be additional and not essential for delivery of the recommendation</i>							LIAISE Team Manager and Specialist Clinical Psychologist	tbc	Not started		
4	That the Commissioners and providers of fetal cardiology services in Wales should review the availability of support for women, including for any transition to Bristol or other specialist tertiary centres. For example, women whose fetus is diagnosed with a cardiac anomaly and are delivering their	CHD Network Clinical Director	Apr '17	Amber – behind plan	Risk that we are unable to get commitment / agreement on the changes that are required across the two hospitals / commissioning bodies Risk that operational challenges	Jun 17 due to delay in engagement with UHW and the operational challenges in their fetal cardiology service	Meeting arranged for 18 th November with English and Welsh commissioners as well as Bristol and Cardiff trusts to establish: <ol style="list-style-type: none"> Commissioner oversight of network Commissioner support for IR actions (4,5 &11) Establishment of working group(s) to address the specific changes in practices required 	CHD Network Clinical Director and Network Manager	Nov '16	Green - complete	Agreed pathway of care in line with new CHD standards and in line with patient feedback
Ahead of the meeting: define specifics of recommendation (e.g. approaches to diagnosis and counselling); options for patient involvement (survey then focus group); CHD standards that relate to this recommendation; examples of practice from other centres							CHD Network Clinical Director and Network Manager	Nov '16	Green-complete		

Progress overview							Detailed actions					
No.	Recommendation	Lead Officer	Completion date	Status	Delivery Risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence	
	baby in Wales should be offered the opportunity, and be supported to visit the centre in Bristol, if there is an expectation that their baby will be transferred to Bristol at some point following the birth				in delivery of the fetal cardiology service in UHW prevent focus on the achievement of this recommendation business plan		University Hospital Wales to define how additional fetal sessions will be delivered and who from fetal cardiology will lead the recommendation implementation and collaborate with Bristol to set up working group in January	Clinical Director for Acute Child Health, university hospital wales	Dec '16	Blue- on target		
							Fetal working group to define changes / new pathways, taking account of patient feedback	Working group	Jan '17	Blue- on target		
								Undertake patient survey and focus groups (FI).	CHD Network Manager	Jan '17 Revised to Feb 17 due to delay in engagement with UHW and the operational challenges in their fetal service	Amber – behind plan	
								Co-design the offer with patient representatives for women whose fetus has been diagnosed with cardiac anomaly and deliver agreed model.	CHD Network Manager	Apr 17	Blue- on target	

Progress overview							Detailed actions				
No.	Recommendation	Lead Officer	Completion date	Status	Delivery Risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
				Amber – behind plan			New pathways in place	CHD Network Clinical Director and Network Manager	Apr '17 Revised to Jun 17	Amber – behind plan	Summary paper showing previous and new ways of working, detailing an assessment of the benefits
5	The South West and Wales Network should regard it as a priority in its development to achieve better co-ordination between the paediatric cardiology service in Wales and the paediatric cardiac services in Bristol.	CHD Network Clinical Director	Apr '17	Amber – behind plan	Risk that we are unable to get commitment / agreement on the changes that are required across the two hospitals / commissioning bodies Risk that lack of paediatric cardiology lead in UHW delays the ability to undertake actions	Final completion delayed to May 17 due to initial delay getting engagement from UHW	Network Manager and Network Clinical Director to contact Welsh Commissioners and University of Hospital of Wales to meet to discuss and agree process including method of monitoring its implementation	CHD Network Manager	Nov 16	Green-complete	
							Set up joint working group set up with Network Team facilitating. UHB, UHW and commissioners to deliver the relevant actions and improvements required for service.	CHD Network Manager	Dec 16	Blue- on target	
							To define the opportunities for improvement in coordination and the actions to achieve this	CHD Network Manager	Dec 16	Blue- on target	
							To undertake a patient engagement exercise (e.g. focus group, survey, online reference group) to test the proposed options for improvement	CHD Network Manager	Jan 17	Blue- on target	
							Deliver actions to improve coordination	CHD Network Manager	May 17	Blue- on target	

Progress overview							Detailed actions				
No.	Recommendation	Lead Officer	Completion date	Status	Delivery Risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
7	The paediatric cardiac service in Bristol should carry out periodic audit of follow-up care to ensure that the care is in line with the intended treatment plan, including with regards to the timing of follow-up appointments.	Deputy Divisional Director	Jan '17	Green-complete	None		Audit proposal submitted to the audit facilitator for inclusion on the Children's annual audit plan	Patient Safety Manager	Aug '16	Green-complete	Audit proposal
							Conduct 1 st annual audit into follow up care for cardiac patients as per recommendation	Patient Safety Manager	Nov '16	Green-complete	Audit report
							Report findings of the audit	Patient Safety Manager	Jan '17	Green-complete	Audit presentation and W&C delivery group Agenda and minutes November meeting
							System developed for the regular reporting and review of follow up waiting lists at monthly Cardiac Business meeting.	Assistant General Manager for Paediatric Cardiac Services	Aug '16	Green-complete	Follow up backlog report, Cardiac Monthly Business meeting standard agenda
8	The Trust should monitor the experience of children and families to ensure that improvements in the organisation of outpatient clinics have been effective.	Nurse Project Lead	Oct '16	Approved as closed by Steering Group (09/01/17)			Baseline assessment (monthly outpatient survey) of current experience of children and families in outpatients reviewed)	Outpatients Experience working group	Aug '16	Green-complete	1. Outpatients and Clinical Investigations Unit Service Delivery Terms of Reference
							Gap analysis of current monitoring vs monitoring required to understand patients experience of the organisation of outpatient's completed	Outpatients Experience working group	Sept '16	Green-complete	2. Outpatients and Clinical Investigations Unit Service Delivery Group

Progress overview							Detailed actions				
No.	Recommendation	Lead Officer	Completion date	Status	Delivery Risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
							Systems in place for regular and specific monitoring, and reviewing and acting on results (FI)	Outpatients & CIU Service Delivery Group	Oct '16	Green-complete	Agenda(3.10.16) 3. Outpatients and Clinical Investigations Unit Service Delivery minutes of meeting (3.10.16) 4. OPD Patient Experience Report (October 2016) 5. Paediatric Cardiology – Non-Admitted RTT Recovery (Appendix 1) 6. Cardiology Follow-Up backlog update (Appendix 7. Project on a Page: Outpatient Productivity at BRHC (Appendix 7)
9	In the light of concerns about the continuing pressure on cardiologists and the facilities and	Divisional Director	Jan'17	Blue- on target	Risk that other sites are unable to share data		Undertake benchmarking exercise with other CHD Networks, reviewing a defined list of criteria including aspects such as: job planning, IT and imaging links, information governance. To include site visits as appropriate	CHD Network Manager	Jan '17	Blue- on target	

Progress overview							Detailed actions				
No.	Recommendation	Lead Officer	Completion date	Status	Delivery Risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
	resources available, the Children's Hospital should benchmark itself against comparable centres and make the necessary changes which such an exercise demonstrates as being necessary.				required to complete a comprehensive benchmarking exercise Dependent on the action required to address the gaps it may not be possible to have implemented all the changes in the timescale.		Identification of actions required to address the gaps	CHD Network Manager	Jan '17	Blue- on target	
							Progress to implementing any changes in practice that are deemed necessary	CHD Network Manager and Divisional Director	Jan '17	Blue- on target	
11	That the paediatric cardiac service benchmarks its current arrangements against other comparable centres, to ensure that its ability, as a tertiary 'Level 1' centre under the NCHD Standards, to communicate with a 'Level 2' centre, are adequate and sufficiently resourced. Benchmarking would require a study both of the technical resources	CHD Network Clinical Director	Jan'17	Blue- on target	Linked to recommendation no.9. Actions detailed under recommendation no. 9 will also achieve recommendation no. 11. Risks to delivery, timescales, progress against delivery and evidence will be the same as per recommendation no. 9						

Progress overview							Detailed actions				
No.	Recommendation	Lead Officer	Completion date	Status	Delivery Risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
	underpinning good communication, and the physical capacity of clinicians to attend planning meetings such as the JCC (Links to recommendation no. 5)										
16	As an interim measure pending any national guidance, that the paediatric cardiac service in the Trust reviews its practice to ensure that there is consistency of approach in the information provided to parents about the involvement of other operators or team members.	Clinical Lead for Cardiac Services and Consultant Paediatric Cardiac Surgeon	Dec '16	Blue- on target			Enhance existing guidance to describe team working and in particular the involvement of other operators and team members in patient care. Review by the Trust wide consent group and Cardiac Clinical Governance for approval and then implement.	Consultant Paediatric Surgeon and Specialist Clinical Psychologist	Dec '16	Blue- on target	
18	That steps be taken by the Trust to review the adequacy of the procedures for assessing risk in relation to reviewing cancellations and the timing of re-scheduled procedures within paediatric cardiac services.	Deputy Divisional Director	Nov '16	Green- complete			Assessment of current process of risk assessing patients who have been cancelled and the timing of their rescheduled procedure	Cardiac Review Programme Manager	Aug '16	Green- complete	Current process review report
							Develop new and improved process for risk assessing cancelled patients ensuring outcomes of this are documented	Consultant Paediatric Surgeon and Cardiac Review Programme Manager	Nov '16	Green- complete	JCC performance review meeting agenda and cancelled operations report

Progress overview							Detailed actions				
No.	Recommendation	Lead Officer	Completion date	Status	Delivery Risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
20	That the Trust should set out a timetable for the establishment of appropriate services for end-of-life care and bereavement support.	Deputy Divisional Director	Nov '16	Green-complete	None		End-of-life care and bereavement support pathway developed (FI)	Deputy Divisional Director	Sept '16	Green-complete	End-of-life and bereavement support pathway
							Implementation and roll out of new pathway	Deputy Divisional Director	Nov '16	Green-complete	Communication and presentations to roll out
21	Commissioners should give priority to the need to provide adequate funds for the provision of a comprehensive service of psychological support	Commissioners		Green-complete (provider actions)			Previous submission to commissioners for psychological support updated	Head of Psychology Services	Sept '16	Green-complete	Submission to Commissions
							Expression of Interest for increased resource to be submitted as part of business planning	Head of Psychology Services / Deputy Divisional Director	Mar'17	Green-complete	Expression of interest and W&C Business plan
23	That the BRHC confirm, by audit or other suitable means of review, that effective action has been taken to ensure that staff possess a shared understanding of the nature of patient safety incidents and how they should be ranked.	Deputy Divisional Director	Dec '16	Blue-on target	None		Review results of Trust wide Manchester Patient Safety (MAPSAF) to understand current baseline for both team level and divisional staff views on patient safety incident reporting and management	Deputy Divisional Director	Sept '16	Green-complete	
							Annual programme- Targeted approach to all staff groups to be developed with implementation of bespoke training and regular updates to clinical staff	Deputy Divisional Director	Dec '16	Blue-on target	
CQ C.2	Provision of a formal report of transoesophageal or epicardial echocardiography performed during surgery	Clinical Lead for Cardiac Services	Nov '16	Amber-behind target		Jan '17 <i>Slippage due to capacity constraints</i>	ECHO form for reporting in theatres implemented	Consultant Paediatric Cardiologist	Aug '16	Green-complete	
							Audit to assess implementation (Nov'16) and request to Steering Group to close	Patient Safety Manager	Nov '16	Amber-behind target	

Progress overview							Detailed actions				
No.	Recommendation	Lead Officer	Completion date	Status	Delivery Risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
CQ C. 3	Recording pain and comfort scores in line with planned care and when pain relief is changed to evaluate practice	Ward 32 Manager	Aug '16	Green-complete 22/11/16-approved for closure by W&C delivery group			Documentation developed to record pain scores more easily	Ward 32 Manager	Jan '16	Green-complete	Nursing documentation
							Complete an audit on existing practise and report findings	Ward 32 Manager	Aug '16	Green-complete	Audit of nursing documentation
CQ C. 4	Ensuring all discussions with parents are recorded to avoid inconsistency in communication. This includes communications with the Cardiac Liaison Nurses, who should record contacts with families in the patient records (links with review recommendation 12)	Head of Nursing	Dec '16	Blue-on target			Work with Cardiac Nurse Specialists to improve recording communication in the patients' medical records and review option of Medway proforma's to support recording in notes	Head of Nursing	Dec '16	Blue-on target	
CQ C. 5	Providing written material to families relating to diagnosis and recording this in the records. (links to review recommendation 3)	Clinical Lead for Cardiac Services	Apr '17	Blue-on target			Linked to recommendation no. 3. Actions detailed under recommendation no. 3 will also achieve CQC recommendation no. 5				
CQ C.6	Ensuring that advice from all professionals involved with individual children is	Head of Allied Health Professionals and Clinical	Jan '17	Blue-on target		Agreed mechanism for including AHP	Assessment of current Allied Health Professionals input into discharge planning for Cardiac Services Audit completed and results to be formulated 27 th October 2016.	Head of Allied Health Professionals	Oct '16	Green-complete	Assessment documentation

Progress overview							Detailed actions				
No.	Recommendation	Lead Officer	Completion date	Status	Delivery Risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
	included in discharge planning to ensure that all needs are addressed.	Lead for Cardiac Services				advice into discharge planning for children within Cardiac Services	Agree with Cardiac Services Team an effective mechanism for including Allied Health Professionals into discharge planning for Cardiac Services. Meeting setup for 4 th November.	Head of Allied Health Professionals and Clinical Lead for Cardiac Services	Nov'16	Blue – on target	Agreed mechanism for including AHP advice into discharge planning for children within Cardiac Services
							Implement agreed mechanism for including Allied Health Professionals into discharging planning for Cardiac Services	Head of Allied Health Professionals and Clinical Lead for Cardiac Services	Jan 17	Blue – on target	Implementation plan delivery report

Key	
R	Red - Milestone behind plan, impact on recommendation delivery date and/or benefits delivery
A	Amber - Milestone behind plan, no impact on recommendation delivery date and benefits delivery
B	Blue - Activities on plan to achieve milestone
TBC	To be confirmed
G	Complete / Closed
FI	Indicates family involvement in the action(s)

2. Trust wide Incidents and Complaints Delivery Group Action Plan – Senior Responsible Officer: Helen Morgan, Deputy Chief Nurse

Progress overview							Detailed actions				
No	Recommendation	Lead Officer	Completion date of recommendation	Status	Delivery risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
26.	That the Trust should explore urgently the development of an integrated process for the management of complaints and all related investigations following either a death of a child or a serious incident, taking account of the work of the NHS England's Medical Directorate on this matter. Clear guidance should be given to patients or parents about the function and purpose of each element of an investigation, how they may contribute if they so choose, and how their contributions will be reflected in reports. Such guidance should also draw attention to any sources of support which they may draw upon.	Chief Nurse	Jan '17	Amber-behind target		Jun'17 additional and amended actions to fulfil recommendation	26.1 Develop an appendix to the Serious Incident (SI) policy defining "link" between Child Death Review (CDR), complaints and SI investigations / reporting, includes adults and children.	Women and Children's Head of Governance	July '16	Green-Complete <i>Approved by delivery group 15.11.16</i>	Link between serious incidents and other investigatory procedures (e.g. Complaints and Child Death Review) July 2016
							26.2 Develop and implement guidance for staff in children's services on standards procedures / practices that need to be followed to provide a high quality and equitable service for all patients / families in the event of bereavement.	Women and Children's Head of Governance	Dec '16	Blue- on target	
							26.3 Develop and implement guidance for staff in adult services on standards procedures / practices that need to be followed to provide a high quality and equitable service for all patients / families in the event of bereavement.	Head of Quality (Patient Safety)	Jul '16	Green-Complete	Guidance for Supporting and Working with patients/families after unexpected death of an adult or a serious incident involving an adult, July 2016 (latest version)
							26.4 Develop 'guidance' / information for families in children's services how the x3 processes of Child Death Review (CDR) / Serious Investigation (SI) / Root Cause Analysis (RCA) investigation inquests and complaints are initiated / managed and integrate (FI)	Women and Children's Head of Governance	April '17	Blue- on target	

Progress overview							Detailed actions				
No	Recommendation	Lead Officer	Completion date of recommendation	Status	Delivery risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
							<p>26.5 Develop 'guidance' / information for staff in children's services on how the x3 processes of CDR / SI / RCA investigation inquests and complaints are initiated / managed and integrate.</p>	Women and Children's Head of Governance	Dec '16	Blue- on target	
							<p>26.6 Develop the above staff guidance for adult patients and families (minus CDR)</p>	Head of Quality (Patient Safety)	Dec '16	Blue- on target	
							<p>26.7 Develop the above family guidance for adult patients and families (minus CDR) (FI).</p>	Head of Quality (Patient Safety)	Apr '17	Blue- on target	
							<p>26.8 Review options for how patients / families can participate (if they want to) with the SI RCA process implement preferred options (FI).</p>	Head of Quality (Patient Safety)	Jun '17	Blue- on target	
							<p>26.9 Implement a process for gaining regular feedback from patients / families involved in a SI RCAs process to understand what it felt like for them and how we can improve the process for them (FI)</p>	Head of Quality (Patient Safety)	Jun '17	Blue- on target	
27	That the design of the processes we refer to should take account also of the need for guidance and training for clinical staff as regards liaising with families and enabling effective dialogue.	Chief Nurse	Jun '17	Blue-on target			<p>27.1 Guidance developed for staff for the preparation and conduct of meetings with parents/families to discuss concerns and/or adverse event feedback</p>	Medical Director	Jun '16	Green-complete	Guidance for the Preparation and Conduct of Meetings with Parents/Families to discuss concerns and/or adverse event feedback, June 2016
							As per actions 26.4 and 26.5, included in recommendation no. 26 to develop guidance for staff				

Progress overview							Detailed actions				
No	Recommendation	Lead Officer	Completion date of recommendation	Status	Delivery risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
							<p>27.2 Develop a framework for training staff to support them to effectively and sensitively manage processes relating to CDR/SI's and complaints. Develop and pilot session.</p> <p>Existing complaints training materials to be reviewed and updated to include guidance on supporting families in circumstances where a complaint is being investigated alongside a CDR or SI. January 2017.</p> <p>Other bespoke training opportunities to be considered in light of development of staff guidance by Children's Services (see 26.5), due April 2017.</p>	Head of Quality (Patient Experience and Clinical Effectiveness) And Head of Quality (Patient Safety)	Jun '17	Blue- on target	
28	That guidance be drawn up which identifies when, and if so, how, an 'independent element' can be introduced into the handling of those complaints or investigations which require it.	Chief Nurse	Dec '16	Blue- on target			<p>28.1 To review UHBristol's previous use of independent review / benchmarking from other trusts to inform above.</p> <ul style="list-style-type: none"> - Complaints - RCA's 	Patient Support and Complaints Manager and Patient Safety Manager	Nov '16 Nov '16	Green- complete	Reports of the Reviews undertaken
							<p>28.2 Develop guidance for when to access 'independent advise / review' for</p> <ul style="list-style-type: none"> - Complaints - SI RCAs 	Head of Quality (Patient Experience and Clinical Effectiveness) And Head of Quality (Patient Safety)	Oct '16 Dec '16	Blue- on target	Complaints policy Serious Incident Policy (appendix 9, pg. 33)
							<p>28.3 The Trust has entered into exploratory discussions with the Patients Association about developing a model for exceptional independent investigation/review. This work will commence with a focus group of previous dissatisfied complainants in</p>	Head of Quality (Patient Experience and	Mar '17		

Progress overview							Detailed actions				
No	Recommendation	Lead Officer	Completion date of recommendation	Status	Delivery risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
							February 2017.	Clinical Effectiveness			
29	That as part of the process of exploring the options for more effective handling of complaints, including the introduction of an independent element, serious consideration be given to offering as early as possible, alternative forms of dispute resolution, such as medical mediation.	Chief Nurse	Apr '17	Blue-on target			<p>29.0 Consider how an independent review can be introduced for 2nd time dissatisfied complainants / involve users in developing a solution.</p> <p>29.1 Visit the Evelina to understand their model for mediation and possible replication at UHBristol. A report will be presented following the visit to consider next steps and possible resource implications.</p>	Head of Quality (Patient Experience and Clinical Effectiveness)	Oct '16	Green-complete	Complaints policy
30	That the Trust should review its procedures to ensure that patients or families are offered not only information about any changes in practice introduced as a result of a complaint or incident involving them or their families and seek feedback on its effectiveness, but also the opportunity to be involved in designing those changes and overseeing their implementation.	Chief Nurse	Dec '16	Amber-behind target		Apr '17 Revised to allow for family involvement	30.1 Develop a clear process with timescales trust-wide for feedback to families / patients outcomes involved in SI panels / review and actions ongoing from this and staff (FI).	Head of Quality (Patient Safety) and Clinical Effectiveness)	Apr '17	Blue-on target	
							30.2 Ensure complainants are routinely asked whether and how they would like to be involved in designing changes in practice in response to the concerns they have raised (FI)	Head of Quality (Patient Experience and Clinical Effectiveness)	Oct '16	Green-complete	

Progress overview							Detailed actions				
No	Recommendation	Lead Officer	Completion date of recommendation	Status	Delivery risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
							30.3 Use of process for asking patients how they would like to be involved in designing changes in practice in response to the concerns they have raised to be audited at the end of February 2017, including review of survey replies.	Head of Quality (Patient Experience and Clinical Effectiveness)	Feb '17	Blue – on target	
							30.4 Regular complainant focus groups to be held from April 2017 onwards as part of routine follow-up of people's experience of the complaints system. Ambition is for these focus groups to eventually be facilitated by previous complainants.	Head of Quality (Patient Experience and Clinical Effectiveness)	April '17	Blue – on target	

Key	
R	Red - Milestone behind plan, impact on recommendation delivery date and/or benefits delivery
A	Amber - Milestone behind plan, no impact on recommendation delivery date and benefits delivery
B	Blue - Activities on plan to achieve milestone
TBC	To be confirmed
G	Complete / Closed
FI	Indicates family involvement in the action(s)

3. Trust wide Consent Delivery Group Action Plan – Senior Responsible Officer: Jane Luker, Deputy Medical Director

Progress overview							Detailed actions				
No.	Recommendation	Lead Officer	Completion date of recommendation	Status	Delivery Risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
12	That clinicians encourage an open and transparent dialogue with patients and families upon the option of recording conversations when a diagnosis, course of treatment, or prognosis is being discussed.	Medical Director	Dec '16	Blue on target			12.1 Guidance developed to medical staff to ensure patients and families are given the option to record conversations when a diagnosis, course of treatment, or prognosis is being discussed	Medical Director	Aug '16	Green-completed	Medical Staff Guidance
							12.2 Review of new existing guidance to reflect the recommendation and include recommendation in updated consent policy , guidance notes and e-learning	Deputy Medical Director	Nov '16	Green-Completed	Consent policy Guidance on consent policy e-learning for consent
							12.3 Incorporate new guidance into existing Children's Consent pathway (existing letter that goes to families before their surgical appointment) (FI)	Consultant Paediatric Cardiac Surgeon	Dec '16	Blue-on target	Letter to families
13	That the Trust review its Consent Policy and the training of staff, to ensure that any questions regarding the capacity of parents or carers to give consent to treatment on behalf of their children are identified and appropriate advice sought	Deputy Medical Director	Jan '17	Blue-on target	E-learning lead is currently on learn term sick which has led to a delay in updating e-learning material		13.1 Trust wide Consent delivery group set up	Deputy Medical Director	Sept '17	Green-Completed	Terms of reference for Trust Wide Consent Group Minutes and actions from meetings
							13.2 Review the consent policy and agree a re-write policy or amend existing policy to ensure patients and clinicians are supported to make decisions together	Consent Group	Nov'16	Green Completed	Revised consent policy ratified by CQC December 2016
							13.3 Develop training and communication plan	Deputy Medical Director	Dec '16	Amber behind but no impact on completion date	Training and communications plan

Progress overview							Detailed actions				
No.	Recommendation	Lead Officer	Completion date of recommendation	Status	Delivery Risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
							13.4 Advice from legal team and safeguarding on revised consent policy and e-learning	Deputy Medical Director	Nov '16	Amber	Legal and safeguarding assurance confirmation
							13.5 Update e-learning for any changes to consent policy and process	Deputy Medical Director	Jan '17	Amber	Updated E-learning package for consent
14	That the Trust reviews its Consent Policy to take account of recent developments in the law in this area, emphasising the rights of patients to be treated as partners by doctors, and to be properly informed about material risks	Deputy Medical Director	Linked to recommendation no. 13, actions, timescales and status as detailed under this recommendation – Blue on target, date completion scheduled Jan '17								
17	That the Trust carry out a review or audit of (i) its policy concerning obtaining consent to anaesthesia, and its implementation; and (ii) the implementation of the changes to its processes and procedures	Deputy Medical Director	May'17	Blue-on target			17.1 Anaesthetic group to be set up to review current practise in pre-op assessment in relation to consent for anaesthesia and how they can implement a consent for anaesthesia process trust wide (FI)	Consultant Paediatric Cardiac Anaesthetist	Dec '16	Blue on target	Minutes and actions from meeting
							17.2 Liaise with Royal College of Anaesthesia and other appropriate professional bodies with regarding national policy	Paediatric Anaesthesia consent group	Jan' 17	Blue-on-target	Correspondence with Royal College of Anaesthetists and Associations
							17.3 Implementation plan for trust wide consent process	Paediatric Anaesthesia consent group	May '17	Not started	

Progress overview							Detailed actions				
No.	Recommendation	Lead Officer	Completion date of recommendation	Status	Delivery Risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
	relating to consent										
CQC. 1	Recording the percentage risk of mortality or other major complications discussed with parents or carers on consent forms	Deputy Medical Director	Jan' 17	Blue-on target			1.1 Review trust wide consent form in use to agree whether they should be amended to improve recording of risk	Consent Group	Dec '17	Blue-on target	Updated / amended trust consent forms
							1.2 Paediatric Cardiac Services to agree whether service would benefit from a bespoke cardiac consent form that includes percentage risk	Consultant Paediatric Cardiac Surgeon	Nov '16	Amber	Agreement of Paediatric Consent Group to utilise bespoke consent forms where appropriate
							1.3 Cardiac Services- agree and implement process for discussing percentage risk with families (FI)	Consultant Paediatric Cardiac Surgeon	Nov '16	Green	Information and consent forms available to parents

Key	
R	Red - Milestone behind plan, impact on recommendation delivery date and/or benefits delivery
A	Amber - Milestone behind plan, no impact on recommendation delivery date and benefits delivery
B	Blue - Activities on plan to achieve milestone
TBC	To be confirmed
G	Complete / Closed
FI	Indicates family involvement in the action(s)

4. Other Actions Plan – governed by the Independent Review of Childrens Cardiac Services Steering Group

Progress overview							Detailed actions				
No.	Recommendation	Lead Officer	Completion date of recommendation	Status	Delivery Risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
22	That the Trust review the implementation of the recommendation of the Kennedy Report that a member of the Trust's Executive, sitting on the Board, has responsibility to ensure that the interests of children are preserved and protected, and should routinely report on this matter to the Board.	Trust Secretary	Sept '16	Green-complete			Review of current arrangements and processes (Sept '16)	Trust Secretary	Sept '16	Green-complete	Executive Lead Role description
24	That urgent attention be given to developing more effective mechanisms for maintaining dialogue in the future in situations such as these, at the level of both the provider and commissioning organisations.	Commissioners and Trust	Jan '16	Blue-on target			Discussion with commissioners about the issues and agreement to mitigate a similar occurrence	Commissioners and Trust	Jan '16	Blue-on target	
31	That the Trust should review the history of recent events and the contents of this report, with a view to acknowledging publically the role which parents have played in bringing about significant changes in practice	Chief Nurse	Oct '16	Green-complete			Trust board paper presented in July acknowledging the role which parents have played in bring about significant changes in practice and in improving the provision of care	Chief Executive	July '16	Green-complete	Trust Board Paper and Trust Board Agenda, July '16
							Presentation to Health and Overview Scrutiny Committee	Chief Executive, Medical Director, Chief Nurse and Women's and	Aug '16	Green-complete	

Progress overview							Detailed actions				
No.	Recommendation	Lead Officer	Completion date of recommendation	Status	Delivery Risks	Revised timescale & reason	Actions to deliver recommendations	By	When	Status	Evidence
	and in improving the provision of care.							Children's Divisional Director			
							Presentation to the Bristol Safeguarding Children's Board	Chief Nurse	Oct '16	Green-complete	
32	That the Trust redesignate its activities regarding the safety of patients so as to replace the notion of "patient safety" with the reference to the safety of patients, thereby placing patients at the centre of its concern for safe care.	Medical Director	Dec '16	Blue- on target			Adoption of the term "Safety of Patients" in place of "Patient Safety" going forward and communication of preferred term Trust wide	Medical Director	Dec '16	Blue- on target	

Key	
R	Red - Milestone behind plan, impact on recommendation delivery date and/or benefits delivery
A	Amber - Milestone behind plan, no impact on recommendation delivery date and benefits delivery
B	Blue - Activities on plan to achieve milestone
TBC	To be confirmed
G	Complete / Closed
FI	Indicates family involvement in the action(s)

Parent Representative Role and Responsibility Independent Review of Children's Cardiac Services Steering Group

1. Introduction

The Trust is responsible for the delivery of 32 recommendations from the Independent Review of Children's Cardiac Services and CQC report (<http://www.uhbristol.nhs.uk/about-us/reports-and-findings-relating-to-the-children's-hospital/>). A Steering Group has been set up, chaired by Carolyn Mills, Chief Nurse and Executive Lead for Children's Hospital, to ensure that the recommendations are delivered in a timely and comprehensive manner.

Parents have played an important role in bringing about significant changes and in improving the care we provide. We would like to work in partnership with parents to help deliver the recommendations of these reports. There are a number of ways we are engaging and involving parents and families in this work, and this includes inviting parent representatives on the Steering Group. Parent representative on the Steering Group will play an important part in supporting and informing the implementation of the recommendations from a parent and family perspective.

2. What is a parent representative?

A parent representative is a member of a group or committee who has personal experience of using health or care services. They offer a different point of view from people who provide or commission health care services.

Parent Representatives are appointed by the hospital to promote openness and transparency by involving and consulting the public in its work.

Parent representatives are not expected to represent the views of the wider community but rather bring a different, lay perspective to the work of the group, which professionals hear and take seriously. They are not constrained by professional protocols and can speak out, but also know how to listen and engage in constructive debate.

Parent Representatives are not paid for their work but are entitled to claim reimbursement of travel costs including mileage or public transport fees and parking.

3. What will I be asked to do?

The role of the parent representative will be to;

- Act as the voice of the parent on the Steering Group, ensuring the interests of the families of cardiac services in the Children's hospital are represented in the implementation and sign off of the recommendations.
- Provide advice guidance and challenge to the Steering Group to help ensure that the family involvement in the implementation has been appropriate, relevant and effective.
- Be part of the virtual parents reference group (please see Cardiac Families Group Terms of Reference for more detail) and to be the link and liaison between the Steering Group and the parents reference group – disseminating information and updating both groups as required.
- Support the assessment of whether a recommendation, should be signed off as effectively completed from a parent/family perspective.
- To engage in the monthly meetings of the Independent Review Steering Group meeting by reviewing the meeting papers and providing input/comments prior to the meeting taking place or by attending the meeting if possible (*Times and dates of meeting currently being reviewed*).
- Maintain confidentiality at all times and to comply with UH Bristol Health & Safety Policy, Information Governance policy, Safeguarding and Equalities legislation and other relevant policies. These will be provided at the commencement of your role.
- As Parent Representatives you are not responsible for the delivery of the recommendations or the delivery of any specific actions.

4. What skills and qualities will I need?

As a parent representative you will need the following skills:

- Willingness to develop an understanding of the work of the steering group and the role it plays in the Trust
- The ability to process and consider detailed information in the form of reports
- The ability to participate confidently in meetings
- The ability to focus on other individuals or on groups and organisations outside of one's own experiences.
- Empathy and the capacity to consider the needs and feelings of others
- Able to give an appropriate time commitment.
- The ability to maintain confidentiality.
- Good communications skills including respect for the views of others and the ability to listen and take part in constructive debate.

5. How will I be supported?

As a Parent Representative you will receive support from the Cardiac Review Programme Manager and the Family Involvement Working Group members. This will include:

- An initial induction to Trust policies and processes.
- Sending of papers for the Steering Group meeting plus the opportunity to discuss these prior to the meeting with the Cardiac Review programme manager
- Individual support to deliver the role, as required, including preparation for meetings and claiming your travel costs.
- A named individual to represent your views when you are unable to attend meetings and to give you feedback on the outcomes
- Ongoing support to identify development opportunities to allow you to develop in this role

You will also have the opportunity to be actively involved in the Congenital Heart Disease Network and other Children's hospital groups should you be interested.

6. Terms of Engagement

To act as a Parent Representative it would be important that you:

- Are able to commit to undertaking the responsibilities above
- Be willing to act in the best interests of all service users, independent of specific personal interests

We will ask you to complete a simple Expression of Interest form to let us know why you are interested in the role and what you would hope to gain from it. We will also ask you to complete a Disclosure and Barring form according to our standard procedures.

7. Duration

This is flexible and can be adapted to suit the individual circumstances. The implementation programme for the review is due to complete in June 2017 with a period of evaluation post implementation which we would expect to conclude by the end of the year.

We anticipate that there will then be further opportunities within the Congenital Heart Disease (CHD) Network to continue in a similar role for any parents who wish to do so. The CHD network links together all the healthcare providers, patients and families in the South Wales and South West region. The networks vision is to ensure high quality, equitable access to care across the region; providing excellent information to patients, families and staff;

collaborating to improve quality; and ensuring that there is a strong collective voice for CHD services.

We are aware that circumstances may change which may influence your ability to be part of this work. We hope that we would be able to support you with any changes or adjustments necessary but should you feel unable to continue with the role at any point, please advise the programme manager

If you would like to become a parent representative, please contact the LIAISE team on 0117 342 7444 or email bchinfo@UHBristol.nhs.uk and we will be happy to contact you to discuss this further.

Terms of Reference – Cardiac Families Reference Group

Document Data		
Corporate Entity	Cardiac Reference Group	
Document Type	Terms of Reference	
Document Status	Final version 1.0	
Hospital Lead	Clinical Chair, Women and Children’s Division	
Document Owner	Cardiac Review Programme Manager	
Approval Authority	Women and Children’s Cardiac Review Delivery Group	
Next Review Date:	Date of First Issue:	Date Version Effective From:
	FINAL v1.0, 29/11/16	01/12/2016
Estimated Reading Time	5 mins	

Document Abstract				
This document provides the Terms of reference for the Cardiac Family Reference Group, giving guidance on the purpose and makeup of the group and identifying duties carried out by the group.				
Document Change Control				
Date of Version	Version Number	Lead for Revisions	Type of Revision	Description of Revision
3/11/16	V0.1	Cardiac Review Family Involvement Group	Content	Content additions/deletions and amendments
17/11/16	V0.3	Cardiac Families	Content	Content additions/deletions and amendments
29/11/16	V1.0	Cardiac Review Family Involvement Group	Content	Content additions/deletions and amendments

What is the Group for?

This group is for supporting developments and improvements in the cardiac service both in Bristol and the wider South West Network.

Who can join this group?

The group is open to patients who are currently accessing or have accessed the cardiac service and their families. This includes both patients seen by a Cardiologist, and those who have undergone cardiac surgery.

How do you become a member?

Please let us know if you would like to become a member by emailing bchinfo@UHBristol.nhs.uk with your name and a contact number. We will telephone you to confirm the additional details we need and then send you the link to join the group. By accepting the invitation you are agreeing to the **Group Guidelines** detailed below.

What does the group do?

- Acts as a voice of the family and provides an objective “sounding board” for the cardiac service to understand their views.
- Brings together families from a wide geographic area to participate in service development where attending meetings and focus groups may be a barrier to engagement.
- Provides a forum to discuss ideas about how to develop and improve the services offered.
- Works together to reach a consensus on the best way to progress specific projects or activities.
- Supports the development of documents such as patient information leaflets, policy and guidance documents and electronic information resources.
- Helps form and facilitate task groups for various activities as and when required
- Reviews and approves, from a family perspective, actions taken as a result of any reports or reviews of the cardiac service either by internal or by external organisations

Where will the outcomes of this group be shared?

Outcomes will be shared on the hospital and Congenital Heart Disease (CHD) network website, via the hospital facebook page, and through the cardiac support groups. They will be included in the CHD network newsletter which will be distributed across the region. The CHD network links together all the healthcare providers, patients and families in the South Wales and South West region. The networks vision is to ensure high quality, equitable access to care across the region; providing excellent information to patients, families and

staff; collaborating to improve quality; and ensuring that there is a strong collective voice for CHD services.

How will the group work?

This is a virtual group which uses facebook as a platform for communication. The group will only be visible to group members in order to protect your privacy. Invitations to join the group will be offered patients who are currently accessing or have access the cardiac service and their families, which will be verified by the clinical team. Your profile will be visible to other group members according to your own personal privacy settings. We will post when we would like you to get involved in pieces of work which may have a specific deadline for responses. There is no obligation or expectation for any of the group members to be involved in any pieces of work that is sent to them. We appreciate that members of the group have many other important commitments and may not be able to participate or get involved in the work at any given time. We respect every group member's right to withdraw their involvement at any time. Access to the group will be limited to group members and the hospital staff that are leading on involving families in this work, namely the Clinical Chair, Specialist Clinical Psychologist, LIAISE team manager and the Cardiac Review Programme Manager. Feedback from the group will be anonymised before sharing wider. Group members can get involved in a variety of different types of work; from reviewing documents to helping design and improve a specific process.

Group Guidelines

1. Any reporting of the discussions that take place in the group will be anonymised and will not contain any information that will identify members.
2. We expect that participants only post comments and commentary that is relevant to the group and the discussions taking place. Members should be respectful to the group community. Administrators will not accept vulgarity, personal attacks or insulting posts and all discussions must remain civil and courteous.
3. Members are expected to respect the privacy of other members of the group and treat any discussions within the group as confidential.
4. The group is not a means of communication with the cardiac team and should not be used to ask questions about diagnosis or treatment. Please speak to your clinical team should you have any questions. Any complaints or comments relating to the service for which you require a response should be directed through LIAISE or the Patient Support and Complaints Team. The group will not act as a support group however it may signpost people to relevant support groups if appropriate.
5. Only upload images or graphics that are owned by yourself and do not upload anything that encourages illegal activity.
6. The administrators reserve the right to remove members, posts, photos and comments from the group. This may be with or without explanation.
7. If any posts are identified which cause concern for an individual's safety the administrator will escalate this concern according to the Trust safeguarding policy.

8. Your participation in this group is at your own risk and you will take full responsibility for your comments and any information you choose to provide.
9. Be careful when providing personal information online. We would strongly advise that you do not upload the following information; full address, DOB, telephone no. national insurance no, school/workplace/birth place/previous addresses.
10. Please be aware that the views of members do not necessarily represent or reflect the opinions of University Hospital Bristol and the wider Congenital Heart Disease Network.
11. Please abide by Facebooks Statement of Rights and Responsibilities (www.facebook.com)

How can I unsubscribe from the group?

At any point you can remove yourself from the online group. Should you wish to re-join at a later date you can contact us on bchinfo@UH Bristol.nhs.uk

[Who will be the administrator for the group?](#)

The Cardiac Review Programme Manager will be responsible for administrating and overseeing this group. This is a hospital employee whose responsibility is to lead and coordinate the implementation of the Cardiac Review and CQC recommendations.

I want to be involved, but not part of this group?

We have a range of options for engagement and participation. Please contact us on bchinfo@UH Bristol.nhs.uk or telephone 0117-3427444 and we will be happy to discuss these further.