University Hospitals Bristol NHS
NHS Foundation Trust

The Report of the Independent Review of Children's Cardiac Services in Bristol

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE (Initial Action)
(1) That any review of the Department of Health's Outlier policy (the policy followed by the NCHDA when its audits trigger alerts or alarms) should give specific attention to the need for publication of the responses to outlier alerts, and of any actions taken as a result.	Department of Health		
(2) That the Trust should review the adequacy of staffing to support NCHDA's audit and collection of data. **Initial Action** Framework for review of staffing requirements; - Changes in staffing during review period - Benchmark with other centres, linking with NCHDA recommendations - Review and report	Trust	Rebecca Dunn, Cardiac Services General Manager and Divisional Governance Lead	September '16

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE (Initial Action)
(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 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.	Trust	Carolyn Mills, Chief Nurse, Executive Lead Children's Services and Senior Responsible Office for Review Recommendation	
Completed Actions 1. Current pathway of information that we give out to patients and families mapped including what we give, when and how. Gaps of information identified by team.			January '15
2. Creation of 4 new leaflets based on gap analysis exercise by team			January '15
3. Review of content of existing information by families via a listening event to identify any gaps and also accessibility of information.			February '15
4. Co-designed with families content of information leaflets and information on the website			February '15

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE (Initial Action)
Initial Action Draft new patient pathway including information and how to access, for review by cardiologists and cardiac surgeons in first instance and then link into next family listening event.			September '16
(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 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. **Initial Action** Correspondence from Network Manager and Network Clinical Director to Welsh Commissioners and University of Hospital of Wales to meet to discuss and agree process/pathway including method of monitoring its implementation.	South West and Wales Network	Dr Tometzki, Network Clinical Director	July '16
(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.	South West and Wales Network	Dr Tometzki, Network Clinical Director	

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE (Initial Action)
Initial Action Network team to work with University Hospitals Wales and University Hospitals Bristol Clinical teams to review coordination between services. Define scope of exercise (based on initial meetings with Cardiff team may include: information and patient leaflets, IT and imaging links, discharge and repatriation processes and escalation, clinical leadership, attendance at meetings and job planning issues, clinical protocols and pathways, clinical governance processes).			October '16
(6) There should be explicit recognition at a national level that children are 'lost to follow up' at points in time other than transition and transfer to other centres, which are the points explicitly reflected in the NCHD's current standard. The standard should be broadened, to recognise the matters of safeguarding which can arise for vulnerable children.	NHS England		
(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. **Initial Actions** 1. Submit an audit proposal following approval by cardiac clinical governance, to the audit facilitator for inclusion on the Children's annual audit plan. 2. Develop system for the regular reporting and review of follow up waiting lists at the monthly Cardiac Business meeting.	Trust	Rebecca Dunn, General Manager Cardiac Services and Divisional Governance Lead	August'16 August'16

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE (Initial Action)
(8) The Trust should monitor the experience of children and families to ensure that improvements in the organisation of outpatient clinics have been effective. **Initial Action** Review baseline assessment (monthly outpatient survey) of current experience of children and families in outpatients to inform scope and focus of improvement plan for organisation of outpatient clinics.	Trust	Carolyn Mills, Chief Nurse, Executive Lead Children's Services and Senior Responsible Office for Review Recommendations	August '16
(9) In the light of concerns about the continuing pressure on cardiologists and the facilities and 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. **Initial Action** Benchmarking exercise and gap analysis with other units and site visits as appropriate - Combine with Network Visit, (e.g. to Southampton). Consider re visit of Leeds.	Trust	Ian Barrington, Women's and Children's Divisional Director	October '16

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE (Initial Action)
(10) NHS England should gather and/or publish, to the extent possible, the data necessary to assess the implementation of the NCHD standard, that tertiary centres should employ one consultant cardiologist per half million people served, working flexibly across the Network.	NHS England		
(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 underpinning good communication, and the physical capacity of clinicians to attend planning meetings such as the JCC. **Initial Action** 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.	South West and Wales Network	Dr Tometzki, Network Clinical Director	December '16
(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.	Trust	Sean O'Kelly, Medical Director	

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE (Initial Action)
Initial Actions 1. Policy/guidance to medical staff to ensure patients and families are given the option to record conversations exploring any legal/governance and reputational issues 2. Incorporate into children's consent pathway			November '16 December '16
(13) That the Trust reviews 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. **Completed Actions** 1. Review of current consent process by families via listening event 2. Co- design of new consent process with families 3. New consent process implemented apart from written risk information which is being agreed by surgeons **Initial Actions** 1. Evaluation of the Cardiac Consent pathway by families run by the Children Services psychology team 2. Written risk information surrounding surgery to be agreed by Cardiac Surgical Team and included as part of the consent process	Trust	Sean O'Kelly, Medical Director	February '15 February-December '15 March '16 March '16- to date September '16

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE (Initial Action)
(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. **Initial Action** Review the consent policy and training to address the issues raised.	Trust	Sean O'Kelly, Medical Director	January '17
(15) That a national protocol be agreed explaining the role of individuals and teams in paediatric cardiac surgery and cardiac catheterisations. Such a protocol should be shared at an early stage of the pathway of care, to ensure that all families are clear about how teams work and the involvement, under supervision of junior members of staff.	Department of Health		
(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. **Initial Action** A team to be established to review the children's hospital consent form.	Trust	Rob Tulloh, Cardiology Clinical Lead	September '16
(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 relating to consent.	Trust	Sean O'Kelly, Medical Director	

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE (Initial Action)
Initial Action 1. Review consent policy with respect to anaesthetic consent 2. Liaise with Royal College of Anaesthesia with regarding national policy			October '16 October '16
(18) That steps be taken by the Trust to review the adequacy of the procedures for assessing risk in in relation to reviewing cancellations and the timing of re-scheduled procedures within paediatric cardiac services. **Initial Action** Assessment of current process of risk assessing patients who have been cancelled and the timing of their rescheduled procedure	Trust	Rebecca Dunn, General Manager Cardiac Services and Divisional Governance Lead	August '16
(19) That NHS England should commission a review of Paediatric Intensive Care Services across England. We were conscious of the heavy strains placed on families by the limitations on the capacity of the Bristol PICU, during the period of this Review, and consider that this is likely to be a national issue that requires proper attention.	NHS England		
(20) That the Trust should set out a timetable for the establishment of appropriate services for end-of-life care and bereavement support.	Trust	Rebecca Dunn, General Manager Cardiac Services and Divisional Governance Lead	

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE (Initial Action)
Completed Actions 1. Appointment of additional bereavement support roles 2. Review of current pathway complete			June '16 June '16
Initial Action New End-of-life care and bereavement support pathway under development			September '16
(21) Commissioners should give priority to the need to provide adequate funds for the provision of a comprehensive service of psychological support. **Completed Actions (Trust)** 1. Cardiac Services psychology needs assessment complete 2. Submission made to commissioners for inclusion in 2016/17 prioritisation **Initial Action (Trust)** Revisit and update previous submission *(Louise Lloyd and Sue Dolby, Heads of Allied Health Professions Women's and Children's Division).*	Commissioners		 September '15 November '15 November '16
(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. **Completed Actions** Refreshed accountabilities for the executive lead appointment for Children's	Trust	Pam Wenger, Trust Secretary	 April '15

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE (Initial Action)
services **Initial Action** Review current of arrangements and processes			September '16
(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. **Initial Action** 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.	Trust	Rebecca Dunn, General Manager Cardiac Services and Divisional Governance Lead	September '16
(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 & Trust	Carolyn Mills, Chief Nurse, Executive Lead Children's Services and Senior	

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE (Initial Action)
Initial Action Discussion with commissioners on how best to achieve this.		Responsible Office for Review Recommendations (Trust)	October '16
(25) That when structural changes to the NHS are made, adequate resources are devoted to organising and archiving records in a way that will enable them to be retrieved and studied at a later date.	Commissioners		
(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.	Trust	Carolyn Mills, Chief Nurse, Executive Lead Children's Services and Senior Responsible Office for Review Recommendations	

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE (Initial Action)
Completed Actions Links between Serious Incidents and other investigations policy written **Initial Action** Development of integrated process for managing complaints and investigations with guidance for families about the function and purpose of each element, how they may contribute, and how their contributions will be used in the report, along with information on support available to them.			July '16 October '16
(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. **Initial Action** Consider and explore sources of training available aiming to prevent breakdown in communications and stand-offs where possible	Trust	Sean O'Kelly	December '16
(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.	Trust	Carolyn Mills, Chief Nurse, Executive Lead Children's Services and Senior Responsible	

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE (Initial Action)
Initial Action Revised complaints and concerns policy includes recommendations on independence, for review by the Senior Leadership		Office for Review Recommendation	August '16
(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.	Trust	Carolyn Mills, Chief Nurse, Executive Lead Children's Services and Senior Responsible Office for Review Recommendation	
Initial Action Initial meeting with Trust Quality Team and Divisional team to discuss best approach.			September '16
(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.	Trust	Carolyn Mills, Chief Nurse, Executive Lead Children's Services and	

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE (Initial Action)
Initial Action Trust wide meeting organised to discuss best approach to involving complainants in devising solutions		Senior Responsible Office for Review Recommendation	July '16
(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 and in improving the provision of care.	Trust	Carolyn Mills, Chief Nurse, Executive Lead Children's Services and Senior Responsible Office for Review Recommendation	
Initial Action Formal paper to the Board and evidence within the action plan**.**			July '16
(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.	Trust	Sean O'Kelly, Medical Director	

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE (Initial Action)
Initial Action Adoption of the term "Safety of Patients" in place of "Patient Safety" going forward and communication of preferred term Trust wide			December '16

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

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE
(1) Recording the percentage risk of mortality or other major complications discussed with parents or carers on consent forms **Initial Actions** 1. Written risk information surrounding surgery to be agreed by Cardiac Surgical Team and included as part of the consent process 2. Review of Trust consent policy	Trust	Sean O'Kelly, Medical Director	September '16 January '17
(2) Provision of a formal report of transoesophageal or epicardial echocardiography performed during surgery **Initial Action** Provide a formal report for transoesophageal or epicardial echocardiography performed during surgery that can be audited.	Trust	Rob Tulloh, Cardiology Clinical Lead	September '16
(3) Recording pain and comfort scores in line with planned care and when pain relief is changed to evaluate practice	Trust	Zoe Trotman, Ward 32 Manager	

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE
Initial Action Complete an audit on existing practise and report findings			September '16
(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) **Initial Action** Work with Cardiac Nurse Specialists to improve recording communication in the patients' medical records	Trust	Hazel Moon/Mark Gonninon, Head of Nursing, Women's and Children's Division	October '16
(5) Providing written material to families relating to diagnosis and recording this in the records. (links to review recommendation 3) **Initial Action** *Please refer to Cardiac Review recommendation 3*	Trust	Rob Tulloh Cardiology Clinical Lead and Andy Tometzki, CHD Network Director	

RECOMMENDATION	LEAD ORGANISATION	LEAD OFFICER	TIMESCALE
(6) Ensuring that advice from all professionals involved with individual children is included in discharge planning to ensure that all needs are addressed. **<u>Initial Action</u>** Assessment of current Allied Health Professionals input into discharge planning for Cardiac Services	Trust	Louise Lloyd, Head of Allied Health Professional, Women's and Children's Division	October '16