



Improving children's
cardiac services in Bristol
October 2017

Respecting everyone
Embracing change
Recognising success
Working together
Our hospitals.

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What were the reviews?

In 2014, an Independent Review of children's cardiac services in Bristol was launched after a number of families raised concerns about the care and treatment their children received as patients at the Bristol Royal Hospital for Children (BRHC).

The review was set up by the medical director of NHS England to look at children's cardiac services at the hospital and its outreach clinics, to learn lessons, and to contribute to the development of national standards of care.

At the same time, the Care Quality Commission conducted an independent audit and review of the medical records of a sample of children who were cared for by Bristol children's cardiac services between January 2012 and December 2014.

What did the reviews find?

The reviews concluded in 2016 and we fully accepted their findings and welcomed their publication as a way of learning from our mistakes.

The reviews criticised the care we provided to some children and the way in which we responded when some families raised concerns.

Although they focused on children's cardiac services, we have, where possible, implemented learning and service changes throughout the organisation, as we recognise the benefits this will bring.

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.

Recommendations

The reports made a number of recommendations, which we have fully achieved, and in some cases exceeded. The recommendations were broadly spread across four categories:

- Women's and children's services
- Consent for surgery
- Supporting families and staff through incidents and complaints
- National and local recommendations for services that the Trust is not directly responsible for but which have an impact on the experience of children and families.

How did we set about improving our children's cardiac service for families?

Working with families, and learning from their experiences, we have made many significant improvements and will maintain and build on them. We want to ensure that every family's experience is as good as it can be.

To ensure transparency and good governance, we developed a detailed plan to act on the recommendations and report our progress to the Trust Board each month.

We set up a group to oversee our progress, involving a number of parent and staff representatives. It was chaired by Carolyn Mills, chief nurse and executive lead for children.

Parents play an important role in improving how we deliver care and their contribution has brought about significant change in how we work. To ensure we involve and work effectively with families, we have also set up a virtual parents' reference group.

On the following pages you can see each of the recommendations together with the improvements we have made and the difference this will make to our patients and their families.

Women's and children's services

Outpatient experience

What the review told us:

That feedback from patients and families about the organisation of outpatient clinics did not always result in changes or improvements to how we ran the outpatient clinics.

What we have done/are doing:

We looked at how we gather patients' feedback in outpatients and what we do with that information. We set up a working group to monitor comments made by families and ensure any changes benefit patients. The group will continue to review patient and family experience. We are also looking into the possibility of holding weekend or evening clinics, which some parents said they would find useful.

The difference this will make to patients and their families:

Patients feel reassured that we listen to their suggestions and are using these to make improvements.

End of life care and bereavement

What the review told us:

We did not always give families the right level of support and care at the right times after the death of a child.

What we have done/are doing:

We have worked closely with families to understand how we can support them better at this extremely difficult time. They have helped us to develop and set out the support we provide following the death of a child and this is outlined in our core offer to families following the death of their child.

Parents have also worked with us to co-design a monthly bereavement drop-in meeting where parents can get support from other parents and professionals.

We have introduced a family support nurse within the palliative care and bereavement team to provide pre-bereavement support and advice for families. The nurse also provides ongoing practical and emotional support to bereaved families.

As part of the Congenital Heart Disease Network, we are ensuring that families receive consistent levels of support in hospitals across the South West and South Wales. We are also developing a clinical guideline for planning palliative and end of life care for children across the network and this is due to be completed soon.

The difference this will make to patients and their families:

That all families will have a consistent service at BRHC and across the network.

This will ensure families receive consistent, high quality support that meets their needs. We have established a weekly bereavement tracking meeting, which monitors all families to make sure they are being offered the right level of support by their lead consultant and key worker, as set out in the core offer.

Ensuring the assessment and treatment of patients' pain is well documented

What the review told us:

Conversations with patients about how well their pain was controlled were not always recorded in notes. This meant that families did not have the evidence or assurance that their child's pain was well managed.

What we have done/are doing:

A new process is in place to measure and record pain at least every four hours, and again within 30 minutes if additional pain relief is given.

Each paediatric ward carries out a monthly audit of documentation to monitor that this happens.

The difference this will make to patients and their families:

This means that staff can closely monitor, and respond quickly to any concerns about a patient's pain.

Ensuring all team members are involved in discharge planning

What the review told us:

There were occasions when letters providing information for patients preparing to leave hospital did not include advice from all team members involved in their care, for example speech and language therapists or psychologists.

What we have done/are doing:

Each clinical team's interaction with the patient is recorded in their notes and on the ward whiteboard. Cardiac patients' electronic records are linked to our overall digital patient record system. This ensures all staff caring for them have access to this information.

All the multi-disciplinary team members involved in a patient's care meet each week. The team reviews all existing and scheduled patients to ensure they are aware of any additional support these patients may need.

We have also appointed a co-ordinator for complex discharges to support patients with multiple needs who are ready to leave hospital to either go home or to facilities closer to their home.

The difference this will make to patients and their families:

Patients and their families can be assured that everyone involved in their care has all the information they need. GPs or doctors who may see patients in other hospitals will also have all of the information they need, which will also help parents to describe their child's needs to other healthcare staff.

Support and information for patients

What the review told us:

We should provide clearer information for patients in a range of formats.

What we have done/are doing:

We have spoken to families to understand their needs rather than assuming we have all the answers and, together, we have reviewed our patient information. It has been updated and is now available in a variety of formats, including digitally. We have also revamped the information that is on our website to support families, worked with families to design a simple visual graphic to explain a patient's journey, and created information sheets about some of the procedures their child may need.

We also ensure that all patient information is reviewed regularly to make sure it is up-to-date.

We have developed readily accessible answers to a list of questions that families frequently ask. They are available on our website and we will continue to add more based on feedback.

We will monitor the comments we receive about the amount of detailed information that is provided to families about the risks of procedures to ensure it does not cause undue distress or concern.

The difference this will make to patients and their families:

Families will be able to access information about their child's care, when they need it, in a format that suits their needs.

Being clear about who is performing a procedure

What the review told us:

That parents weren't always clear who was going to be performing an operation or procedure and whether there were going to be other professionals, such as junior doctors, assisting.

What we have done/are doing:

We reviewed how we discuss operations and procedures with patients as well as the information we give them to check that we clearly explain who will be involved.

Where possible we do our best to tell families if the surgeon or consultant they have met will not be available on the day of the operation or procedure so they can decide if they want the operation or procedure to go ahead (if it is appropriate for it to be postponed).

We have updated patient information leaflets for children's cardiac surgery and cardiac catheterisation to help staff who talk to patients and their families about this.

We will continue to gather feedback from families to ensure we are giving them the information they need to make decisions about their child's care.

The difference this will make to patients and their families:

Patients and their families will have a clear understanding about the people involved in their treatment and why this may sometimes need to change. They will know that they can discuss any concerns they have with them.

Reviewing cancelled patients

What the review told us:

There wasn't always a consistent way of ensuring that patients who had their surgery or procedures cancelled were rebooked in line with their clinical urgency.

What we have done/are doing:

We understand how distressing it is for patients and families when surgery needs to be cancelled and rebooked so we now review every cancellation and ensure that we rebook it within the timescales advised by the surgeon.

We review the patients affected by cancellations on a weekly basis and record these discussions to ensure that cancelled patients are given equal priority to those whose surgery is at the planning stage.

In addition, we have checks in place to help prevent patients having their surgery or procedure cancelled a second time.

We will continue to review our booking processes to reduce the number of cancellations, as we know how disruptive and upsetting this is for the whole family.

The difference this will make to patients and their families:

Patients and their families will be reassured that we are doing all we can to limit the number of cancelled operations and procedures, and rebook within appropriate timescales.

Communication about follow-up care

What the review told us:

That patients did not always receive their follow-up appointments or planned surgery and interventions at the time the consultant indicated they needed it.

What we have done/are doing:

We have reviewed our entire follow-up waiting list to ensure that patients are receiving treatment at the times the consultant has requested. We have introduced extra cardiac catheter sessions to ensure we can see more patients and have added an additional surgical and pre-operative assessment clinic each week.

We plan to introduce more outpatient clinics to meet growing demand. Each consultant is reviewing their waiting list to ensure there is a clear treatment plan for every patient. We are also improving the way we monitor waiting times each month to ensure patients are treated promptly.

The difference this will make to patients and their families:

This should reassure patients' families that, where possible, they will receive their treatment at the times they have been told they will and if this is not possible we will find a solution quickly.

Psychological support

What the review told us:

That we did not always have sufficient psychological support for our patients and their families and that we should approach commissioners (who decide which services to fund) to enable us to recruit an additional psychologist.

What we have done/are doing:

We have recruited two new psychologists and both have started work at the Trust.

Our aim is to ensure families receive paediatric psychological support from pregnancy to transition into adult services, where the adult psychology service will take over.

We will work with other organisations in the South West and South Wales to ensure families have information about other psychological support services available to them.

The difference this will make to patients and their families:

The two additional psychologists in the team will enhance the high quality psychological support to families and we will ensure other sources of support are more readily available.

Ensuring echo reports from theatre are available

What the review told us:

Reports written by cardiologists of echo imaging were not always available to consultants on the ward or intensive care unit. This meant the consultants did not always have all the information to hand to make the best possible treatment decisions.

What we have done/are doing:

We have created a new echo record form that stands out in patient records so that it is available immediately to consultants. We have improved processes so that the echo record is easily available at subsequent hospital admissions or outpatient appointments. We will audit the effectiveness of this each year.

The difference this will make to patients and their families:

Consultants have all the clinical information available to them when they need it and can make the best possible decisions about how to treat patients.

Improved working between UH Bristol and children's cardiac service providers in Wales

What the review told us:

That communication between UH Bristol and paediatric cardiac service providers in Wales was not always good. This meant that some families did not always have a smooth journey through their child's care.



What we have done/are doing:

We have gathered feedback from families involved in services across the two areas and have reviewed pathways and processes against national standards set for congenital heart disease to identify gaps and areas of learning.

The paediatric cardiac team at the University Hospital of Wales has received additional funding to increase its clinic capacity and members of the team now attend meetings – in person or via video conference – where their patients are being discussed. We have reviewed the information given to families across the region to ensure it is consistent.

We plan to introduce a focus group for families following a fetal diagnosis of congenital heart disease to discuss improvements and learning.

We intend to hold a quarterly multi-disciplinary team meeting with teams from Bristol and Wales to share learning.

The difference this will make to patients and their families:

By improving and increasing the frequency of communication between UH Bristol and children’s cardiac service providers in Wales, we will provide families with a better, more consistent approach to their child’s care and treatment.

Supporting our data collection processes

What the review told us:

That nationally, the process for analysing data and scrutinising it for cardiac patient outcomes was improving to ensure that data submitted was complete and accurate but that the team submitting the paediatric cardiac data was overstretched and may not be able to respond to this increased demand.

What we have done/are doing:

We have reviewed the duties carried out by the team, removed any tasks they no longer need to do and provided more resources. We have made it easier to submit data and we will review the team’s resources regularly to ensure they can respond to increased demand.

The difference this will make to patients and their families:

We can provide comprehensive and accurate data about outcomes for our cardiac patients.

Documenting conversations

What the review told us:

We didn’t always share important information about patients between all members of the paediatric cardiac team because not all conversations were recorded in a consistent format or place.

What we have done/are doing:

We have reviewed how clinical conversations are documented in our clinical records to ensure they are available to all members of the children’s cardiac team involved in each patient’s care.

We have set up a page for the paediatric cardiac team to use on the Trust’s electronic patient record system so that the information documented is available to each member of the children’s cardiac team, including out-of-hours staff.

This may be rolled out to other teams across the hospital to improve communication between members of the team. We plan to regularly check how well the conversations are documented.

The difference this will make to patients and their families:

The paediatric cardiac team now documents conversations in our clinical records in a standardised way to ensure information is shared between all members involved in a patient’s care.

Comparing ourselves to other services

What the review told us:

That we should compare ourselves to other similar services in terms of working practices, facilities and numbers of patients per consultant.

What we have done/are doing:

We compared our services with similar facilities. Members of the cardiac management team and network team formed a group and visited a similar site to compare how we were doing in terms of working practices, facilities and numbers of patients per consultant. The group has developed an action plan and meets monthly to monitor progress. The group reports back to the children’s hospital assurance group.

We will continue to compare our services with other similar hospitals to make further improvements.

The difference this will make to patients and their families:

We continue to improve and learn from other similar hospitals to provide services at UH Bristol that are comparable or better than in other parts of the country.

Consent for surgery

Option for patients to record conversations with clinicians

What the review told us:

That patients should be given the chance to record conversations with doctors so they could listen back and review the information they had been told.

What we have done/are doing:

We have updated Trust guidance on this to make it clear that patients and families are allowed to record conversations with doctors.

We have updated our patient information leaflets so patients and their families are aware they may ask for a conversation to be recorded. We have trialled recording conversations and include the recordings in our electronic patient records.

The difference this will make to patients and their families:

We give the option of conversations being recorded, meaning patients and families do not have to remember everything they are told, which should make understanding very complex and challenging information a bit easier. Ensuring parents and family members are fully involved in and able to make decisions about consent.

Ensuring parents and family members are fully involved in and able to make decisions about consent

What the review told us:

That the Trust should review its approach to discussing consent for procedures so that families are well informed and supported in a partnership approach to the decision-making process regarding their child's treatment. It also said that the hospital process for informing and gaining agreement to consent for treatment did not have specific guidance on how to proceed in the rare situation where a family member may not be capable of making decisions for the patient.

What we have done/are doing:

Our training programme has been developed to include support for doctors to have difficult conversations with families. Training has also been improved so that it meets current regulations and national best practice and includes new video-based training.

The difference this will make to patients and their families:

Patients feel fully informed and supported in the consent process and are involved in making decisions about their care. Vulnerable patients and their families receive the

extra support they need to make the right decisions for them and their family.

Ensuring that families have access to information about the risks of procedures

What the review told us:

We did not always provide families with enough information about the risks of proposed procedures to inform their decision-making.

What we have done/are doing:

All of the Trust's consent to treatment forms have been reviewed to include a section on risks. We have designed additional information sheets for paediatric cardiac patients, which now provide very detailed information about the risks and benefits of proposed procedures.

We know that not all families will want to know this level of detail so we ensure that families only have access to the information if they want it. We will gather more feedback about the information sheets to ensure they meet families' needs.

The difference this will make to patients and their families:

We are providing more information to families to support them to make decisions about their child's treatment options.

Reviewing the involvement of the anaesthetic team in the consent process

What the review told us:

That our processes for obtaining consent lacked clarity and consistency in the completeness of information provided.

What we have done/are doing:

We have reviewed practices against national guidance and now include more detail about the risks of anaesthesia in consent information.

We now regularly involve anaesthetists in paediatric cardiac pre-operative assessment clinics. We will ask families for feedback about the impact of having an anaesthetist present at pre-operative assessments. We will also review the impact of these improvements to try to minimise the number of cancellations due to clinical reasons.

The difference this will make to patients and their families:

We are providing more information so families are better informed about, and prepared for, their child's proposed procedures.

Supporting families and staff through incidents and complaints

Recording patient safety incidents accurately

What the review told us:

That there was not a consistent understanding by all staff about how to assess, grade and report a potential patient safety incident, meaning that the senior management team did not always have the most accurate picture of safety concerns.

What we have done/are doing:

We now provide a training package for staff to improve their knowledge of how to assess, grade and report patient safety incidents. The training is delivered to all staff groups at the children's hospital.

The training is combined with the existing Trust patient safety training programme and the Trust's patient safety team will continue to monitor and review the quality and accuracy of incident reporting to ensure it is effective.

The difference this will make to patients and their families:

Patients will feel confident that if members of staff raise any concerns, they are accurately raised to the appropriate managers quickly so action can be taken to ensure the safety and quality of services.

Involving patients and families in improvements after complaints or incidents

What the review told us:

That we could do more to ensure patients and families are actively involved in designing solutions to improve our services when things have not gone as well as we would want.

What we have done/are doing:

We have worked with families to enhance the way we involve them in service improvements. This includes asking anybody who would like to make a complaint, or is affected by a serious incident, whether they would like to be involved in the investigation and any actions carried out as a result.

We will run workshops with patients and families so they can review how well we have addressed their complaints and whether the improvements we have made will prevent future complaints or incidents. This will be audited and form part of our patient experience work plans.

The difference this will make to patients and their families:

Our aim is that families will feel fully involved in efforts to improve services and be assured that any changes we make will meet the needs of patients and families.

Responding well when things go wrong

What the review told us:

The process for managing complex complaints, serious incidents or investigations into the death of a child can be very confusing and difficult for families. There are often lots of different processes that are taking place, both within and outside the hospital, and it is difficult for families to understand what is happening. The review also found that staff did not always have the skills and expertise to discuss complaints or incidents with families as well as possible; it felt that the opportunity for an independent investigation or mediation may be useful in some cases.

What we have done/are doing:

We are working closely with families to understand what they need from us when things may not have gone as planned.

We now allocate a dedicated case manager to work with families all the way through this process.

Our training for staff has been updated to help them manage these processes in a sensitive and informed way. Changes have also been made in adult services so the families of adult patients have this level of support and guidance.

Clear guidance has been developed about when an independent view may help provide clarity and assurance for families.

We are speaking to staff at other hospitals to understand how and when they use medical mediation to support families and plan to use this learning to make improvements for our patients.

The difference this will make to patients and their families:

While some aspects of the process cannot be changed, as they are part of legal or regulatory requirements, we are ensuring the concerns of families are central to our work. Through our case manager, we will ensure families receive clear updates throughout the complex process for complaints, serious incidents and investigations.

Other recommendations

Acknowledging the role which families have played to lead to changes in practice and improvements to care

What the review told us:

The Trust should consider the history of the events leading to the review in order to acknowledge the impact of the families on bringing about change and improving the care we provide.

What we have done/are doing:

We publicly acknowledge everything that families have done to help us learn and make improvements both in practice and the care we provide, particularly those who raised concerns that led to the reviews.

Our LIAISE team (a dedicated patient and family support service for the children's hospital) has worked very closely with families who have been part of the reviews to help improve our services.

The views of families are embedded in the improvements we have made.

Family representatives have been part of our steering group which oversaw the delivery of the recommendations of the independent review.

We have two virtual reference groups. The first of these reviewed all of the new or updated documents that we produced as part of this review. Their comments, and the time that they have dedicated to us, have been invaluable.

The second group reviewed the patient-facing information, such as the patient pathways and our website, and we are grateful for their efforts to help us make improvements in these areas.

The LIAISE team and the network management team worked with our local cardiac support groups to run two extremely successful listening events in Gloucester and Exeter which have helped us to focus on what families need from us.

The LIAISE team engages with young people who use our services to ensure we are meeting their needs and develop improvements as a result of this feedback.

The difference this will make to patients and their families:

Families will understand how much we value their input and their support on this journey of improvement. We will continue to proactively involve families who want to help us make improvements and plan to expand their involvement into other services.



The importance of children's services at the Trust's executive board

What the review told us:

That the Trust would benefit from having a member of the executive board with the explicit responsibility to ensure that the interests of children are preserved and protected, and that they should routinely report on this matter to the board.

What we have done/are doing:

The role of the Trust's chief nurse as the executive lead for children was reviewed and strengthened. Our chief nurse regularly updates the Trust Board about the progress of these improvements and other issues affecting children's services.

The difference this will make to patients and their families:

There is a regular voice for children's services at the highest level in the Trust and, where necessary, action is taken to ensure our services are of the highest quality.

Placing patients at the centre of what we do

What the review told us:

That we should now refer to 'the safety of patients' so that patients remain at the centre of what we do.

What we have done/are doing:

Patients are the focus of all of our work on safety and we have made a number of changes to ensure our patients are always the focus. This includes reviewing and updating relevant documentation and job descriptions.

The difference this will make to patients and their families:

We're committed to maintaining the safety of our patients and keeping them at the centre of everything we do.

The importance of good communication between the Trust and commissioners

What the review told us:

That the communication between commissioners, who decide which services to fund, and the Trust was not always as good as it could be, especially in relation to communication with families who had reason to complain to our commissioners.

What we have done/are doing:

NHS England, which leads the NHS in England, has developed guidance to ensure families who need to complain have a designated point of contact.

The Trust and our commissioners work together to ensure we provide the best support possible for families and to learn when something has not gone to plan.

The difference this will make to patients and their families:

We and our health partners are committed to listening and providing support for patients and their families when concerns are raised.

What next?

We have made a number of improvements but we are not complacent and know there is still plenty more we can do to ensure our services are as safe, compassionate and kind as possible.

We have developed new ways of monitoring our performance and will continue to ensure we meet or exceed the recommendations that were made in the reports.

We will continue to work with parents who have been involved in our reference group to make further improvements to our services.

We will also ask parents for their feedback to help us develop future projects that involve patients, parents and family members.

How to get involved

Please contact our LIAISE team (a dedicated patient and family support service for the children's hospital) to find out how you can get involved:

Telephone: 0117 342 8065

Email: bchinfo@uhbristol.nhs.uk

Post:

LIAISE Family Information Room
Level 2
Bristol Royal Hospital for Children
Paul O'Gorman Building
Upper Maudlin Street
Bristol BS2 8BJ





twinkle
little star
all the little stars
twinkle twinkle

things that make me happy...

- 1. Spending time with my family
- 2. Going to school and learning new things
- 3. Playing with my friends
- 4. Reading books
- 5. Watching the sun set
- 6. Listening to music
- 7. Spending time with my friends
- 8. Being with my family
- 9. Being with my friends
- 10. Being with my family

Love from,
Amber and my Mummy and Daddy xxx



Bristol Royal Hospital
For Children



University Hospitals Bristol
NHS Foundation Trust

Respecting everyone
Embracing change
Recognising success
Working together
Our hospitals.

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