Cardiology in the Young

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Evaluating the congenital heart assessment tool: a quality improvement project

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Original Article

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Abstract

Background: An early warning tool, the Congenital Heart Assessment Tool (CHAT), was designed in 2012 to support parental preparation before discharge, enhancing understanding of their infant's complex CHD, the signs of deterioration to look out for and to support decision-making at home. Acceptability and feasibility of the tool were tested during 2013–2015 in a single centre. *Aim of this project:* To evaluate the wider implementation across four children's cardiac centres of the CHAT for infants with complex CHD in the community setting. *Design:* A four-centre collaborative mixed-methods quality improvement project funded by The Health Foundation, during 2016–2018. A plan, do, study, act cycle of improvement was employed. This article reports on the planning phases, creation of a modified tool (CHATm); and the implementation phases, including retrospective case note review using CHATm; tabletop simulation exercise using CHATm and clinical implementation of CHATm. *Results:* Key findings included the benefit of using CHATm simulation for practitioners; the effectiveness of CHATm in predicting amber and red triggers, indicating parental actions and escalation of concerns to professionals. Parents using CHATm found it enhanced knowledge in preparation for going home, supported decision-making, and discussions with health care professionals. *Conclusion:* Using the CHATm clinically identified the need to develop a structured model of assessment of parental suitability for home-monitoring programmes. A robust and nationally agreed training programme for all staff using CHATm was recommended to ensure successful and complete implementation in practice.

Approximately one-third of infants born with CHD will need urgent surgery in infancy and those who present in a poor condition are at the highest risk from the procedures.[1] During the decade 2000–2010, the paediatric cardiac surgery case mix became more complex with an increased prevalence of functionally univentricular hearts, high-risk diagnoses, and low weight at operation (<2.5 kg).[2] The National Congenital Heart Disease Audit[1] (2020) reports 284 Norwood procedure surgical cases during 2016–2019 in the United Kingdom and Ireland, with a 93% 30-day survival (n = 264); equivalent to approximately 95 cases per year across the United Kingdom. Infants with these complex conditions have the highest mortality and morbidity between the first and second operations, remaining fragile after their first surgery and in the early weeks after discharge home.[3]

Parents need to be adequately prepared for discharge during this critical time and supported at home between the first and second stage of surgery.[4–6] However, parents can find it challenging to follow an escalation plan, despite education and training when their child is discharged home.[4] In addition, parents can feel that their concerns about their infant are not taken seriously and that local health professionals do not always have the knowledge and information to respond quickly or appropriately.[4,7]

The original Congenital Heart Assessment Tool (CHAT)[6,7] was developed in 2012 by a group of clinicians, parents and CHD charity members, using the principles of paediatric early warning scores and a national traffic light tool.[8–11] It is a community-based early warning tool using a traffic light system to support decision-making by parents, carers and community teams and escalate early signs of deterioration in infants with complex CHD as part of a home-monitoring programme (HMP). The CHAT was designed for use with a specialist group of infants with complex functionally univentricular CHD.[7] These infants have emergency surgery soon after birth or post-natal diagnosis and will usually require at least two further heart operations. Infants are most fragile between the first and second surgery, the interstage period, due to the single ventricle being dependent on the flow of blood through a shunt and the young age of the infant.[12]

Vigilance by families and carers in optimising the outcome of their infants in the first year of life within this patient group has been demonstrated.[13,14] Enhanced surveillance and early identification of deterioration in physiology reduce mortality risks and support optimal growth to undertake second-stage cardiac surgery.[12,15] Single centre studies report a reduction in interstage

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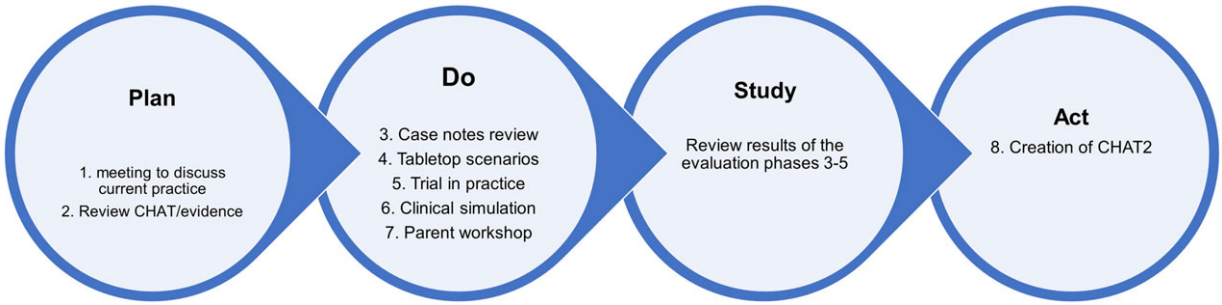


Figure 1. The plan, do, study, act cycle.

mortality using a HMP, which enhances surveillance and early escalation of concerns.[16–19] This interstage period is when HMP and the CHAT are used to enhance safety, quality of care and care efficiency.

Empowering patients to engage with community services is a priority in new models of care.[20] Projects that bridge inpatient and outpatient care are crucial to meet the needs of our future infants and families in the current National Health Service climate. Implementation of the CHD Standards and Service Specifications[21] was a key driver for this quality improvement project. The patient and family involvement groups from the National Health Service England review[22] raised concerns about the inconsistency across services and the need to raise standardisation by care bundles and pathways between different centres and across inpatient/outpatient care. The review[22] also highlighted the importance of keeping care close to the patient's and family's home, which could be met in part with HMPs.

At the time of planning this quality improvement project, there were no other community-based early warning tools available for use by parents or carers of infants with complex CHD in the United Kingdom. There remains a gap in the research regarding early warning tools for parents and carers in the community setting; however, there is potential for the CHAT to be implemented nationally.

The principal aim of the collaborative quality improvement project was to enhance safety mechanisms for these fragile infants. The secondary aim was to evaluate the wider implementation of an early warning tool (CHAT)[7] within a HMP for infants with complex CHD in the community setting, across four children's cardiac centres.

The objectives of the quality improvement project were:

1. To review the content of the CHAT[7] (phases 1 and 2)
2. To further evaluate the effectiveness of CHAT and incorporate CHAT into the discharge planning and current HMPs in the four children's cardiac centres (phases 3–5)
3. To provide an updated standardised tool (CHAT2) to assess infants and escalate concerns (phase 8)

Materials and method

Design and setting

A mixed-methods quality improvement design using a plan, do, study, act (PDSA) cycle of improvement[23] was undertaken (Fig 1).

The project was conducted over an 18-month period between 2016 and 2018, comprising a 3-month planning phase (August–October 2016) and 12 months implementation (do/study) phase (November 2016–October 2017) at four specialist children's surgical centres and the University of Worcester. The implementation phase was extended to include stakeholders attending the Little Hearts Matter open day (March 2018).

Funding was received from the Health Foundation 'Innovating for Improvement' programme, which aimed to initiate measurable improvement by applying scientific methods within healthcare settings.[24] National Health Service ethical approval was not required as it was assessed as an improvement project in agreement with each of the individual children's cardiac units' Quality Improvement Teams and the University of Worcester Institute of Health and Society Ethics Committee.

Planning stage

The "planning" stage included two review phases to meet the first objective:

1. Cardiac nurse specialists meeting to discuss baseline HMP practice in the four centres (phase 1)

At baseline (August 2016), a national HMP did not exist in the United Kingdom for infants with complex CHD. One of the centres did not discharge their fragile infants between stages 1 and 2 of cardiac surgery, resulting in an extended inpatient stay, increased inpatient costs and bed occupancy. Furthermore, whilst the other three HMPs were based on models of care from the United States of America[16,17], the Cardiac Nurse Specialist teams identified variations in practice. For example, educational packages were delivered to parents before discharge, but there was a lack of structured assessment of parental/carer suitability for the HMP. Furthermore, only one centre was using the definition of "clinical consultation" to code for income generation.

2. Review of the CHAT[7] and discussion with paediatric early warning system experts (phase 2)

The project lead (LS) reviewed the original CHAT[7]; the "Sepsis 6"[25] and the "fever in the under 5s" guideline[26] and asked clinical experts who had developed the paediatric early warning tool[27] and paediatric observation priority scoring system[24] to review the CHAT. Chapman's team[27] had identified the importance of "parental concerns" in the assessment of children and young people and during communication with a clinical professional. At the end of this planning stage, the CHAT was modified (CHATm) with addition of a sixth domain "parental response" and changes to the font, size, layout and to some of the wording to reduce complexity and enhance parental understanding (Fig 2).

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Modified Congenital Heart Assessment Tool (CHATm) – January 2017

Parental response	Parents/ carers happy with their baby	Parents / carer concerned about their baby, there may be no visible changes in the baby condition	Infant very unwell or not breathing call 999 for ambulance start Basic Life Support assessment
Action	Green – carry on normal care	Amber – if any of these signs are present ring for advice from your Cardiac Nurse Specialist 0800 – 1600 hrs or Cardiology Ward – evenings, weekends, bank holidays if in doubt call 999	Red - if any of these signs are present ring 999
Behaviour	• Behaves normally • e.g., content/smiles (as normal) • Stays awake or awakens quickly (as normal) • Normal crying, easily soothed	• Quieter than usual • Sleeping more than normal or less easy to settle • Less responsive during normal activity • Slightly irritable, unable to comfort	• Not responding to usual interactions • Does not wake or if roused does not stay awake • Weak or floppy • High-pitched or continuous cry or no crying at all
Skin Colour Warmth	• Babies usual colour of skin, tongue, especially lips and nails • Your baby's usual warmth of hands and feet • Normal temperature between 36.5 – 37.5 C	• Blue tinge around mouth or fingertips, paler than usual, or skin is mottled • Sweaty skin or cooler hands and feet than usual • Temperature more than 37.5 – 38 C or below 36 C	• Very mottled, pale, blue, or grey skin • Very cold, sweaty, or clammy • Very puffy eyes, hands, feet, or tummy • Very sunken 'soft spot' • Temperature more than 38°C
Breathing	• Usual breathing rate and effort for your baby • No cold symptoms, such as runny nose	• More breathless, faster, or slower breathing rate • Has cold symptoms, runny nose, cough, noisier breathing than normal • Sucking in skin below ribs or in the neck area more than normal • Nasal flaring	• Not breathing or struggling to breathe or exhausted, cannot cry • Very noisy breathing, grunting, or gasping • Severe 'sucking in skin' below ribs or neck, head bobbing, tracheal tug
Oxygen saturations	• Oxygen saturation range normal for your baby • 70 – 75 % Oxygen saturation	• Oxygen saturation above or below the range for your baby on two consecutive readings 30 minutes apart	• If oxygen saturations persistently above or below the normal range for your baby or you are unable to obtain an oxygen saturation reading
Feeding Nappies	• Baby feeding normally and regularly wet and dirty nappies • Wakes for feeds and is hungry • No vomits, unless small posits are normal • Weight increasing as expected	• Any diarrhoea or vomiting, including vomit after medications, or not keeping feeds down • Struggling to feed, taking longer to feed, breathless on feeding, or sweaty during feeding • Nappies not wet or dirty with usual nappy changes • Has lost weight or weight unchanged or more weight increase than expected	• Vomiting or diarrhoea twice in a row • Cannot feed • Dry nappies for 4 hours or more • Blood in nappy

Figure 2. The modified CHAT (CHATm).

Do stage: The intervention methods and participants

Due to the small number of infants requiring surgery for a functionally univentricular heart annually in the United Kingdom[1] and going home until the second stage of surgery, the "do" stage was designed to compensate for this by using a variety of implementation measures to test the effectiveness of the CHATm (objective 2).

Phases 3, 4, and 5 are presented in this paper; phases 6 and 7 in paper 2[28]

3. Case note review using CHATm
4. Tabletop simulation exercise using CHATm
5. Parental use of CHATm at home
6. Clinical simulation exercise
7. Parent simulation workshop

Participants and methods

Phase 3 Case note review. The method of evaluation was a retrospective review of clinical notes documented during June 2016 till June 2017. Firstly, the project team determined whether each centre had documentation that was coded according to the definition of "clinical consultation"[29] and only case notes coded in this way were included in the review (n = 462).

A standardisation exercise using 10 clinical scenarios and the CHATm was conducted with the review team (by LS) before the case notes were reviewed. The review team included experienced Cardiac Nurse Specialists (n = 3) and qualified Advanced Nurse Practitioners (n = 3).

Phase 4: Tabletop exercise. Simulation was used as the investigative methodology[30,31] to assess the feasibility and usability of CHATm in practice. Ten simulated clinical scenarios were created (by LS) using real examples, including a sample of red, amber, and green triggers.

A convenience sampling strategy was used to invite health care professionals, who met the following inclusion criteria, to participate:

1. Work in a cardiac network (surgical centre, cardiology centre, or local centre)
2. Have an interest in paediatric cardiology (work outside of a cardiac network)
3. Have a fragile infant on their caseload (community teams)

Paper or electronic copies of the 10 scenarios were provided to participants (n = 52) with a copy of the CHATm. Participants

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Table 1. Examples of CHATm triggers in clinical records (phase 3)

CHATm level alert	Scenario	Outcome
Amber	Mother called from her GP for advice. She felt infant had a cold and needed medication	Talked directly to GP infant otherwise well on assessment, signposted to what to do if becomes unwell, given antibiotics in case became unwell, asked to go to hospital if they are started and call the tertiary hospital. Follow up call booked.
Amber	Mum called to say infant vomiting after feeds over the past night and previous day. Infant unsettled and restless continuous crying. Phone assessment made, anti-reflux medication optimised for weight and review feeding and vomiting by telephone this evening. Evening called Mum, infant feeding better with small posits.	Brought in earlier to cardiac clinic to assess medication change and to review infant. Feeding observed and weight assessed Weight the next week continued to increase. Infant more settled appears well. Follow up call booked
Amber	Grandmother and CCNT called infant appears well, taking milk feeds and has wet nappies. Felt cooler this morning and behaviour difficult to settle. CCNT assessed for dehydration. Feed witnessed and taken well, she felt infant still hungry. Milk volumes recalculated and higher calorie milk given. Infant more settled and taking feed less aggressively.	Reviewed by CCNT team the next day and telephone consulted with the tertiary hospital and dietician lead. No ongoing concerns, good weight increase. Infant settling more easily. Due for surgical date after MRI booked. Follow up call booked
Red	Admitted from local clinic with clinical dehydration, required fluids overnight, possible transition to oral diet, fluids need to be maintained, discharged next day. No other concerns.	Local assessed infant for dehydration and intercurrent illness. Admitted overnight for observations. Contacted tertiary centre for further advice and cardiac echocardiogram planned with earlier surgical review. Cardiac Nurse Specialist to call and assess feeding for the next few days. Dietician referral made.
Red	Mum called early & reported baby does not seem well, lower oxygen saturations than expected, taking less feed, not sleeping, difficult to settle and restless. She does not have a thermometer to take the temperature, but infant feels warm, hands and feet cool. CCN present for review called ambulance.	Local assessment admitted for dehydration and treated for intercurrent illness, 2-day admission. Required Nasogastric feeding for 5 days. Called tertiary hospital for further advice. Weight gain poor. To be booked to earlier clinic for cardiac review.
Red	Feeding volumes dropped, minimal wet nappies overnight, not taking feeds, Mum called from local hospital to say in A & E, parents took baby. Baby very unresponsive on arrival.	Reviewed by local ANP who called for cardiac information. Infant kept in for 3 days. Suspected intercurrent illness. Antibiotics given, Nasogastric fluids until taking feeds well, more settled discharged home day 3. Mum called to say she had taken baby into local. Local hospital aware of infant. Complex psychosocial needs

ANP = Advanced nurse practitioner; A & E = Accident and emergency department; CCN = Children's Cardiac Nurse; CCNT = Children's Cardiac Nurse Team; GP = General Practitioner

were asked to spend a maximum of 15 minutes to decide upon the red/amber/green rating for each scenario and were asked to additionally provide written comments on each scenario. Participants were asked to return the completed scenarios to the project lead.

Phase 5. Parental use of CHATm at home. A purposive sampling strategy was employed. During November 2016–August 2017, parents of infants deemed suitable for discharge home after clinical, psychosocial, and safeguarding assessment were invited to use CHATm by the Cardiac Nurse Specialist Team. Exclusion criteria were parents with psychosocial issues, non-English speaking or who could not understand the CHATm. Participating parents were prepared for discharge by the Cardiac Nurse Specialist team using the standard discharge advice, the standard HMP preparation, and the CHATm. Parents were asked to assess their infant using the CHATm daily and to give feedback about using the CHATm to the Cardiac Nurses Specialists, who were asked to record any amber or red triggers initiated by these parents.

Data analysis

Descriptive statistical analysis was undertaken for phase 3 and affinity mapping[32] was used to analyse the data arising from phases 4 and 5.

"Study" stage

Phase 3. Case notes review

The review team identified n = 462 documented "clinical consultations" for review, using CHATm. A total of 38 triggers, red (n = 24), and amber (n = 14), were identified. Examples of these triggers are provided in Table 1.

Phase 4. Tabletop scenarios

Participants (n = 52) included cardiac network nurses (n = 24), medical staff (n = 11), and health care assistants (n = 2); paediatricians with an interest in paediatric cardiology (n = 6) and community nurses (n = 9). Ten scenarios were given to each participant (n = 520 scenarios). In total, 508/520 (99%) scenarios were

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Table 2. Phase 4 Comments about "tabletop scenarios"

	Comments	Health Care Professional
1	*"Training needs to be short and to the point and standardized, the nurse that set me up to do these scenarios gave very clear instructions"*	Nurse
2	*"Contact number needed for professional support or to help understanding if unsure, for HPAs who are not currently part of the HMP training package"*	Medical
3	*"Workshop on this would be great, plus to learn more about this patient group . . . .I would also like to learn more about using this tool and would be very willing to be part of any training or roll out"*	Nursing
4	*"Really liked the traffic light idea, this is clearer than the wording, but I expect if you have training and know your baby it would be more intuitive to use. You would want families calling for support/help earlier rather than later and a clear pathway for them to access HCP either through their local teams or their cardiac centre"*	Nursing
6	*"Wording could be addressed however it maybe that every professional has a view and . . . the wording should reflect the largest user, parent, carer, community care teams"*	Medical
9	*"I thought as a new HCA I would not be able to do this task, but it was very helpful in helping me make a decision for this baby in a simple format. I had a lovely nurse who trained me first. I would not usually do this in my role so it was interesting to try this out in safety. I hope I got them correct"*	Health Care assistant
10	*"Agreed standardization training would be helpful at a national level. Keep it simple and accessible"*	Medical
11	*"Where would I access help"*	HCA
12	*"This is not an alternative to good clinical assessment, but I think it would allow you to work in collaboration with the family who have training and some knowledge to alert health professionals when their baby is not well"*	Nursing
13	*"Really enjoyed the scenarios, make me think hard and apply myself"*	Visiting professional
14	*"This would have been helpful with some of the decisions I have made in the past with families and their infants who I have cared for from xxx"*	CCNT
15	*"Some of the boundaries between Amber alert and Red appear unclear. Although saying that, I was able to score them easily in the scenario. I think training will be crucial to success and clear escalation planning"*	Medical
16	*"I still do not think these babies should be at home, but the more support in the care package they can have and access the safer will be their will be in their care in the community setting "*	Visitor professional
17	*"I am impressed that parents use this system. They must be very knowledgeable about their infants "*	Nursing

completed, and all identified the correct green/amber/red trigger for each scenario.

Comments received included: *"Easy to use and understand, clear to follow and score" (nurse); "Very useful tool for community support teams" (community nurse); "Great way to work with the family, parent, carer" (HCA); "What happens if you do not speak English or read English?" (HCA2).* Other responses related to training and education for staff and parents, escalation process and contacts and clarity of the descriptions in the CHATm (Table 2).

Phase 5. Parental use of CHATm at home

During November 2016 to October 2017, parents of infants being prepared for discharge following complex surgery (n = 12) were identified. Six families were assessed by the medical, nursing, and psychology teams as not suitable for participation due to psychological issues (n = 3), their understanding of CHATm (n = 1), or English not first language (n = 2). Six families participated (white British n = 1, white European n = 3, Bangladesh n = 1, Pakistan n = 1).

Most of the parents (83%, n = 5/6) used the management guidance in CHATm appropriately to raise amber and red concerns. The amber triggers (n = 3) initiated contact with the tertiary centre or the Cardiac Nurse Specialist. The red (n = 3) triggers (Table 3) all resulted in hospital review or admission; however, one of these parents phoned the cardiac nurse specialist first before taking their infant to the local hospital. Parents' feedback regarding their use of CHATm suggested that they found the CHATm training useful before discharge and did not need to use the CHATm every day, only when they were concerned (Table 4).

"Act" stage

This QI project evaluated the efficiency, effectiveness, and usability of the CHATm through five intervention phases (3–7). Phase 3 (*case notes review*) provided active involvement, learning, and exposure to CHATm for the Cardiac Nurse Specialists and Advanced Nurse Practitioners involved in the care of these infants and families, developing their confidence in using the CHATm. Phase 4 participants (*tabletop exercise*) perceived a benefit of practically using the CHATm through simulation; they recognised how the CHATm could effectively indicate amber and red triggers, the action required and escalated parents' concerns to professionals. In phase 4, participants identified that robust and nationally agreed training for all staff that will use the CHATm is necessary to ensure successful and complete implementation. Suggestions relating to the definitions and words used within the CHATm and how to fully prepare parents to use the CHATm were also provided.

In phase 5 (*parental use of CHATm*), a key finding was the need to develop a structured and standardised model to assess parental suitability to go home with the HMP and CHATm. Parents using CHATm explained that whilst they might not use the tool daily, it provided useful knowledge and information prior to discharge from hospital and in preparation for going home. They felt that

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Table 3. Examples of CHAT triggers for families at home

CHAT level alert	Situation	Outcome
Red	Unable to obtain oxygen saturations reading, hands and feet cool, a few "small vomits". Infant quieter than usual. Not interested in feeding.	Mother rang the CNS with information. As unable to feed taken to local hospital for review.
Red	Infant not well, not feeding, cold hands and feed, cannot get oxygen saturation reading, breathing unusual, not very active. Mother called 999 ambulance.	Admitted to local hospital. Respiratory arrest on arrival
Red	No weight gain, complex home environment. Mother and father felt that infant was feeding.	Admitted to local for review of feeding.
Amber	Weight loss no weight gain	Called by community team, admitted to local for feeding review and early cardiology clinic review.
Amber	Issues with feeding, getting tired not taking enough milk feed volume overnight. Mum wanted to discuss.	Long discussion with mother, taken to local hospital. NG tube reinserted whilst not taking enough milk orally and tiring. Booked into early cardiology clinic.
Amber	Infant very restless, not settling, looks hungry, but feeds short bursts and stops. Does not appear breathless. Visited by CCN possible reflux.	Taken into local for review of feeding and reflux issues. Assessed for dehydration and feeding tube passed.

CCN = Children's Cardiac Nurse; CNS = Clinical Nurse Specialist; NG=nasogastric

Table 4. Phase 5 Parents' comments about CHATm

Quotes	Parent/ carer
"The CHATm tool was useful knowledge before I left hospital but on a daily basis I am not thinking are we on green or amber. I ring ward or helpline if I have a question."	Mother 1
"Useful information for knowledge during training whilst in hospital for preparing for going home. Not sure I would use it daily or in an emergency situation".	Mother 2
"with the training in hospital, I just thought this was what all mothers did who had babies who needed an operation . . . it came to me when I was at home with (baby) that I had to make these decisions on my own . . . however weekly contact with a specialist nurse to ask advice and talk through my issues was a big help, we sort of, sorted out a set of discussions between us and when to call each other. Just knowing my (baby) was in Amber supported my decision and that it supports me as a mother, but I don't think it would have changed what I did. "	Mother 3
The information my cardiac nurse specialist showed and taught me was far beyond my expectations, going home was daunting but exciting. I wanted to be a "normal "Mum at home with Baby X, but realised this transition was a huge risk and relied on my skills and abilities. I felt confident in the team and with the processes in place to support me. The different coloured system I used when I was not sure, but did not use this tool daily. I used as a support for my daily decisions and assessments of Baby X and when working with the named cardiac nurse specialist. There is only so much time in a day, the rest I want to love my wonderful baby.	Mother 4
English is not my first language, but I would like to make comments via my interpreter. I did not want to stay in the hospital for nearly 4/12. I was keen to go home. The training package and the tools I was given to help me keep an eye on my baby's health was very good. The patience of the team ensured I have the most xxx (special) times with my baby and have my family and children together. What more could a mother wish for.	Father
The coloured tool I was trained to use it very useful, but I would not use it every day, only when I have concerns over my baby and I want to get to the next surgery safely. I have an excellent nurse who see me twice a week and links with my cardiac specialist team.	Mother 5
My community children's nurse and I go through the assessment every time we meet. My Baby X is doing so well. God Bless me and my new baby.	Mother 6

the tool also supported their decision-making and discussions with health care professionals.

As a result of specific feedback about the content and format of CHATm, further modifications were made, resulting in the creation of a finalised second version of the CHAT in the final "Act" stage of the project (referred to as phase 8). This was called "CHAT2" and is presented in paper 2[28].

The expert consensus arising from the discussions (phase 1) led to creation of a standardised "bundle of care" (Fig 3), incorporating three components: parental assessment/education, the HMP and consideration of individual risks. The CHATm was included within each component, which was updated to CHAT2 at the end of the PDSA cycle (phase 8 presented in paper 2). The further development of CHAT2 contributes to the vision to develop robust bundles of care to support acute specialised care in the community setting, using a virtual ward environment and standardising children's cardiac pathways.[21,33] It also contributes to setting national cardiac safety standards at discharge.[20] The development and implementation of a National standardised "bundle of care" for these infants need further evaluation.

During the 'Act' stage, collaboration with the National children's CHD standards review group was initiated. Preliminary meetings were held with commissioners regarding Univentricular Commissioning for Quality and Innovation[34]

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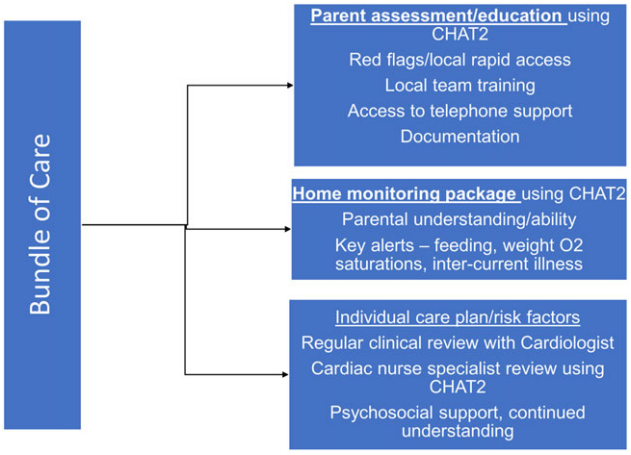


Figure 3. Bundle of care.

and this encouraged involvement of Paediatricians with Cardiac Expertise. The aim of these early discussions was to add the CHAT2 into the Commissioning for Quality and Innovation[34] and expand the remit to support a wider infant group, supporting wider national engagement. In the London network, a dialogue was initiated with the rapid response lead paediatricians for unexpected child deaths regarding the CHAT2 and the proposed Home Monitoring Bundle. The project group engaged with the wider children's community services, with feedback from paediatricians with expertise in Cardiology, Community Children's Nurses, Health Visitors, and nursing assistants.

The introduction of electronic records and wider electronic documentation[35] at a national level will be beneficial to communication across all care domains. However, there remains a lack of electronic connections between tertiary and primary care, which makes real-time working a continuous challenge, especially if an infant is sick or deteriorating. It also places increased pressures on the infant's family to hold health records and specialist knowledge. Development of a mobile application for parents to measure, transmit, and record parent assessment using CHAT2 to the clinical teams through a virtual ward environment[21,33] would address some of these challenges. Several grant applications since the project ended in 2018 have so far been unsuccessful. Unfortunately, the clinical impact of the COVID-19 pandemic during 2020 and 2021 has further hampered progress in terms of wider communication about the project. Development of a mobile application may also support parental electronic records.

There is potential for translation of CHAT2 into different languages; extension of the tool for all infants and young children being discharged after cardiac surgery; and potential to develop another version for older children following later stages of surgery.

Limitations

A challenge encountered was an underestimation of the diversity of service provision across the four centres and the increased time and resources needed for effective communication at a national level. For future similar studies, we would include regular telemedicine links in the costs. This would have helped mitigate some of the time and logistical issues the team faced in terms of getting together.

Furthermore, the project demonstrated challenges relating to families not using the CHATm because they do not understand or speak English; therefore, future work needs to include translation of CHAT2 into different languages to meet the ethnic diversity of this population.[36]

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Conflicts of interest. None.

Ethical standards. Agreement was received from each of the individual children's cardiac units' Quality Improvement Teams and Ethical Approval from the University of Worcester for phases 6–7.

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