

# Innovating for Improvement

Title: Evaluating an Early Warning Tool:  
setting the standard of safe care for  
infants with complex heart conditions at  
home

Organisations:

Great Ormond Street Hospital for Children NHS Trust

University Hospital of Southampton NHS Trust

The Freeman Hospital, Newcastle upon Tyne Hospitals  
NHS Trust

Birmingham Women's & Children's NHS Trust

Little Heart Matters

University of Worcester



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## About the project

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### Project title:

Evaluating an Early Warning Tool: setting the standard of safe care for infants with complex congenital heart disease at home

### Lead organisation:

Great Ormond Street Hospital for Children NHS Trust

### Partner organisation(s):

University Hospitals Southampton NHS Foundation Trust

The Freeman Hospital, Newcastle upon Tyne NHS Foundation Trust

Birmingham Women's & Children's NHS Foundation Trust

Little Heart Matters

University of Worcester

### Project lead(s):

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## Contents

About the project .....	5
Part 1: Abstract.....	7
Part 2: Progress and outcomes .....	8
Part 3: Cost impact .....	23
Part 4: Learning from your project .....	26
Part 5: Sustainability and spread .....	30
Appendix 1: Resources and appendices.....	34
Appendix 2: Project finance .....	35



## Part 1: Abstract

The CHAT2 is a community based early warning (EWT) “traffic light system” to support decision making by parents /carers & community teams across six domains, to escalate early signs of deterioration in infants with complex congenital heart disease (CHD) as part of a Home Monitoring Programme (HMP).

Infants with complex CHD disease, single ventricle and shunt dependent physiology, account for less than 110 infants per year, with the highest mortality and morbidity between the first and second operations (3-5 months). Risks are reduced by the use of a HMP enhancing surveillance and early escalation of concerns (Ghanayem 2004, Giardini 2015).

Currently there are no other community EWTs for infants in the community setting for parents/carers, supported by a current literature review (October 2017).

The successes for the team have been:

- Enhanced collaboration and learning, working at a national level
- Opportunities to trial in note reviews, table top scenarios, video simulations and clinical practice
- Engagement and commitment across tertiary and primary care
- Active feedback from parents/carers and service users
- No additional deaths or risks reported during the study period
- Ignite interest from other tertiary cardiac centres and local services
- Positive impact on HMPs

The main challenges we encountered were an underestimation of the diversity of service provision and the increased time and resources needed for effective communication at a national level.

### Impacts

- The safe and supported discharge of infants with complex CHD
- Presentations of our work both nationally & internationally
- Collaboration with the national children’s CHD standards review group
- Initial meetings with commissioner regarding Univentricular CQUIN
- Involvement of Pediatricians with Cardiac Expertise
- The future development of an App

*(Words 258)*

## Part 2: Progress and outcomes

This exciting innovative project aimed to test the wider implementation of an early warning tool (EWT) for infants with complex congenital heart disease (CHD) in the community setting as part of a four site collaborative improvement project via Home Monitoring Programmes (HMP). It aimed to support the decision making of parents/carers and community teams, to ensure safer, high quality care and effective decision making, bridging highly specialised and general paediatric community based services. The tool was previously part of Dr Kerry Gaskins, PhD (2016).

Currently there are no other community EWTs for use in infants with complex CHD in the community setting or for parents/carers. A current literature review (updated October 2017) did not highlight any new tools in clinical use,

Meakins 2015 and Rempel 2012 both demonstrated the vigilance by families / carers in optimising the outcome of their infants in the first year of life within this patient group. Hehir 2013, stated that enhanced surveillance and early identification of deterioration in physiology, reduced mortality risks. In addition they supported optimal growth to undertake second stage cardiac surgery.

The development of the CHAT2 is a contributor to the national health service vision to develop robust bundles of care to support acute specialised care in the community setting by using a "virtual ward environment" and standardizing a children's cardiac care pathways. In addition CHAT2 contributes to setting national cardiac safety standards at discharge.

### Defining the infant group

CHAT2 is designed for use in a specialist group of infants with complex CHD (Gaskin 2016). The group consists of infants with CHD resulting in:

- single ventricle physiology
- shunt dependant physiology (Little Hearts Matter 2017) .

A normal heart would have biventricular functioning, 2 pumping chambers and no shunt. The following diagnosis are inclusion criteria:

- Hypoplastic left heart syndrome
- Hypoplastic right heart syndrome
- Tricuspid atresia
- Complex pulmonary atresia



- Univentricular heart (double outlet or double inlet ventricle)
- Other CHDs where it is not immediately clear whether the infants heart will take biventricular or single ventricle surgical pathway

These infants have emergency surgery soon after birth or post-natal diagnosis and will usually require further heart operations. Between the first and second cardiac operation is called the first stage surgery or “interstage “ period. This interstage period usually lasts 3-5 months depending on the individuals surgical plan. This time period is when the infants are most “fragile” due to the one pumping heart chamber (single ventricle), dependent on the flow of blood through a tube or shunt as well as complex surgery and the young age of the infant. This 3-4 month period is when HMP and the CHAT2 would be used to enhance safety, quality of care and care efficiency.

### **How the CHAT2 works (Appendix 1- CHAT2)**

**CHAT2** is set out using a traffic light system **red** (emergency), **orange** (seek advice) and **green** (continue usual care). There are 5 physiological parameters and a parental concern parameter. The tool is laid out in a grid format.

- Activity of infant
- Skin color & warmth
- Breathing
- Oxygen saturations
- Feeding & nappies
- *Parental concern*

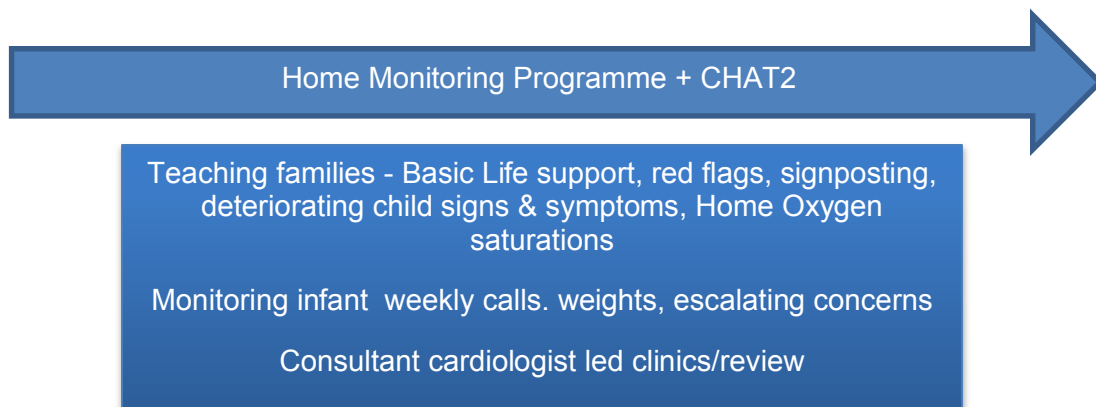
Parents/carers response to the parameters will be one of the 3 levels of action, green, orange or red. Parent/carers are taught to make at least a daily assessment of their infant or at any time their infant is not well and then how to action their decision supported by CHAT2.

It is expected that community care teams will also use CHAT2 supporting joint decisions making. From previous parental workshops, there was a request for no totalling of scores and the response is via a single alert of the colour code (Tregay 2016).

NIHR Infant Heart Study by Tregay 2016 highlighted infant safety:

- *“it is essential for families to be able to identify signs and symptoms and access timely and appropriate medical care”*
- *“health professionals locally must have the knowledge and information to respond quickly and appropriately to parental concerns”*
- *“symptoms recognised by the parents /carer can be under recognised by the professionals”*

## Diagram 1 – Variation in Home Monitoring Programmes

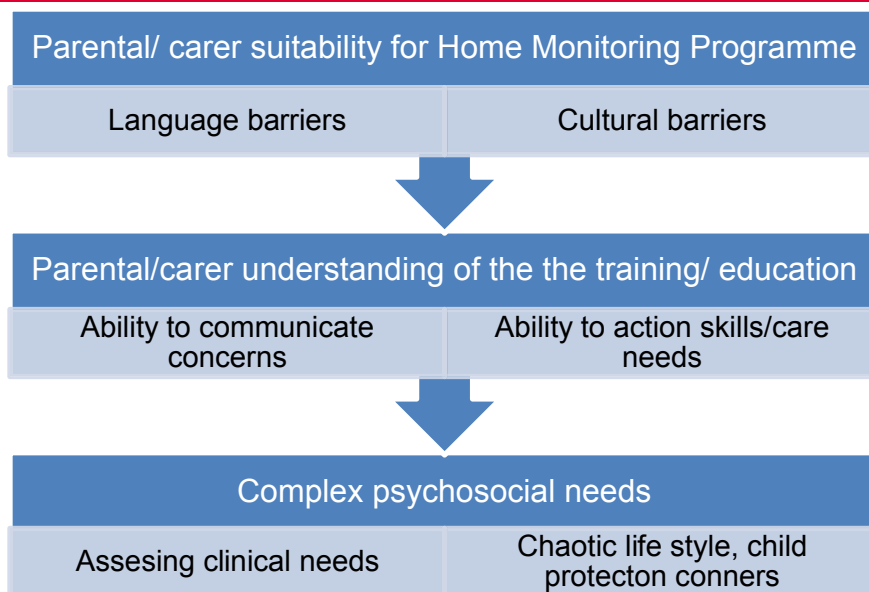


The teams noted at individual site meetings that the diversity of the HMPs was wider than expected (**Diagram 1**). Currently there is no national agreement and the majority of programmes are based on models of care from the United States of America. This resulted in a varied amount of base line work by the each team prior to starting the project before adding CHAT2 to their current HMP, **Diagram 3**.

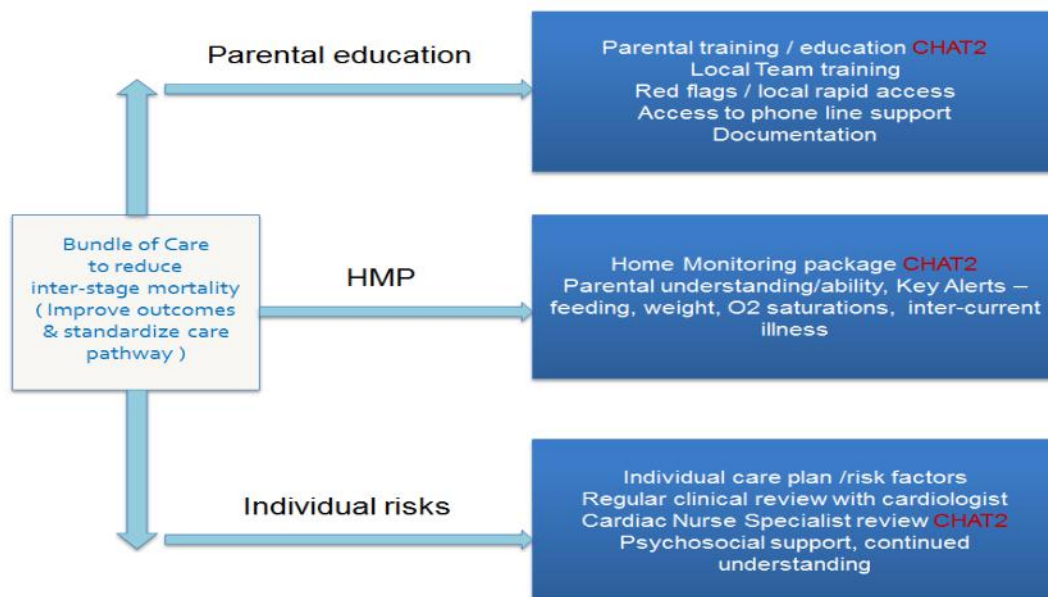
Cardiac Nurse Specialists in each centre with a remit to work with this complex CHD group of infants currently deliver education to parents/carer as part of their HMP.

This resulted in the noted gap of a structured assessment for parental/carer suitability and an educational package (**Diagram 2**). Regular meetings/communications between cardiac centres allowed the sharing of good practice & prevented reproduction of work already in place at an individual centre.

## Diagram 2 – Parental assessment for a Home Monitoring Programme



**Diagram 3 – Home Monitoring Programme - Bundle of care with CHAT2**



The group needed to ensure safety of this patient group & acceptability by professionals and parents/carers. In addition we wanted to build on work already undertaken by Gaskin 2016 & Tregay 2016. As specialist nurses we also wanted to ensure feedback directly influenced quality and efficiency of CHAT2, using a continuous PDSA cycle from professionals and parent/carers.

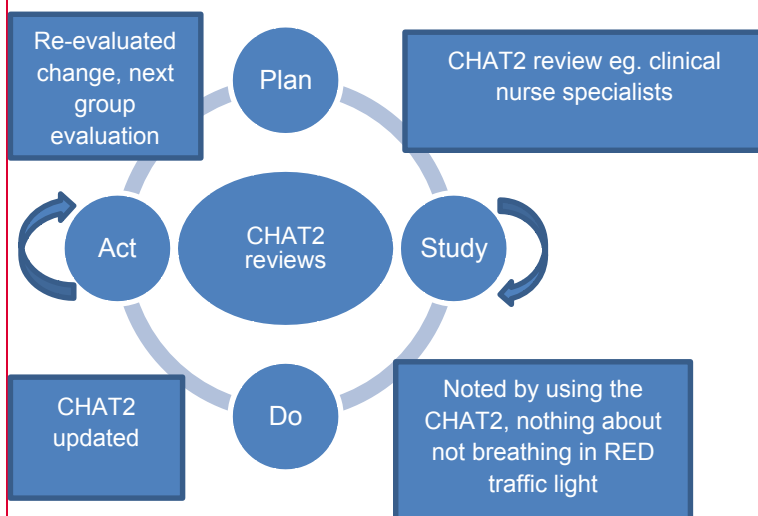
Diversity was highlighted across the centres, from a standardized HMP at discharge home to HMPs in place but not currently discharging infants and families home. This resulted in an extended inpatient stay for some infants and their families. Increased inpatient costs and bed occupancy as well as the

family and infant not spending time in their home environment. For this team the success of this project was very important to them providing, support and learning from other centres at this point in their learning curve. Parents/carers of these infants were also very passionate about this move, as highlighted from the comments.

*“I had never acknowledged how precious the time was with my baby at home until my daughter had her second stage surgery.”* **Parent of infant discharge home.**

Trialling CHAT2 within case notes, and scenarios provided exposure across the clinical teams and disciplines involved in these infants care, and enables staff to be actively involved with CHAT2. In addition we knew the predicted number of infants would be low during the time frame of the project and hence unpredictable & this approach provided a wider scoping opportunity for CHAT2. Engaging parents/carers in the CHAT2 supported their understanding and engagement in rapid real time PDSA cycles of improvement, **Diagram 4**.

**Diagram 4 – Continuous PDSA cycle of improvement**



**CHAT2 – evidence base, review**

The CHAT2 consists of six domains within a traffic light system to support decision-making and escalation of care concerns (Appendix1). We reviewed and embedded aspects the national “Sepsis 6 “work (BMJ 2017), the national under 5’s fever tool (NICE 2017) into CHAT2. It was viewed by clinical experts working with paediatric EWT & Paediatric Observation Priority Scoring developments (Chapman 2016, Dr D Roland). This resulted in the addition of a sixth domain “parental response”. Chapman’s team stated that “parental concerns” are increasingly important in the assessment of children and young people and the communication to a clinical professional.

## CHAT2 – format of tool

The CHAT2 experienced five big changes in format over the first 9 months with feedback from professionals, clinical staff and parents/carers. These included:

- font, colours, size
- practical tool layout/disseminated such as ease of use, storage and access
- changes in wording to reduce complexity and enhance understanding

## CHAT2 – trial using clinical record

CHAT2 was trialed using a retrospective review of clinical records from documented clinical assessment at telephone or recorded face to face consultation. The aim was to test the triggers of CHAT2.

2 centres records could not use CHAT2, due to local documentation and formatting systems.

**Table 1- clinical record reviews using CHAT2**

Number of documentation notes	Total number of documented consultation calls reviewed	Number of correct triggers (red or amber)	Number of incorrect triggers or missed triggers (red or amber)	Level of trigger			Types of examples
				Red	Amber	Other	
24	462	38	0	24	14	0	See below

**Table 2 - examples of CHAT2 triggers in clinical records**

CHAT2 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

		<p>hospital if they are started and call the tertiary hospital.</p> <p>Follow up call book.</p>
Amber	<p>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.</p>	<p>Brought in earlier to cardiac clinic to assess medication change and to review infant. Feeding observed and weight assessed</p> <p>Weight the next week continued to increase. Infant more settled appears well.</p> <p>Follow up call booked</p>
Amber	<p>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.</p>	<p>Reviewed by CCNT team the next day and telephone consulted with the tertiary hospital and dietician lead.</p> <p>No ongoing concerns, good weight increase.</p> <p>Infant settling more easily.</p> <p>Due for surgical date after MRI booked.</p> <p>Follow up call booked</p>
Red	<p>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.</p>	<p>Local assessed infant for dehydration and inter current illness. Admitted over night for observations. Contacted tertiary centre for further advice &amp; cardiac ECHO planned with earlier surgical review.</p> <p>Cardiac Nurse Specialist to call and assess feeding for the next few days.</p> <p>Dietician referral made.</p>
Red	<p>Mum called early &amp; 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.</p>	<p>Local assessment admitted for dehydration and treated for inter-current illness, 2 day admission.</p> <p>Required NG feeding for 5 days.</p> <p>Called tertiary hospital for further advice.</p>

	CCNT present for review called ambulance.	Weight gain poor.  To be booked to earlier clinic for cardiac review.
Red	Feeding volumes dropped, minimal wet nappies over night, 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 inter-current illness. Antibiotics given, NG 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

The case note review provided learning, exposure, feedback and developing confidence in the use of the CHAT2 from a wide range of professional groups.

### CHAT2 - Table top Scenarios, simulation

Fifteen table top scenarios (paper or electronic) and a clinical scenario workshop, hosted at Worcester University targeted a range of professionals with and without experience of this patient group.

### Table 3 - Table top scenarios, staff groups

Professional Group	Numbers completed
Nurses	24
Community nursing teams	9
Medical staff	11
Health care assistants	2
Visitors	6
Total	52

### Table 4 – Quotes from text linked to table top scenarios

Quotes	Professional
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<i>“It was good to practically use the CHAT2 and see it correctly escalating information from families and also health professions involved in the babies care, another armoury in our support programmes for these very vulnerable infants...”</i>	Community paediatrician with cardiology expertise (PEC)
<i>“there needs to be a robust and nationally agreed training for CHAT2 use.”</i>	Cardiac nurse specialist
<i>“The CHAT2 tool is excellent and in a good format for parents to use. Will the parents have an (oxygen saturations) sats monitor at home? If not then this will cause anxiety that they don't know the (oxygen) O2 levels. If they find their baby is in Amber then can they call their local hospital ie assessment unit and be reviewed there. Ours would have open access to the assessment unit?”</i>	Community paediatric nurse
<i>“Saturation parameters 70-75% doesn't reflect some of our patients with saturations 75-85%. Will these CHAT2 tools be individualised to (the) patient on discharge?”</i>	Nurse on the ward

52 scenario papers with 10 scenarios were given out with the CHAT2 and 50 completed. Before completion there was a 5 minutes review of the CHAT2 tool and were given a maximum of 15 minutes to complete. Each scenarios sheet had green, amber and red scenarios based on real consultations. Each scenario has a space for comments or concerns. 12 individual scenarios were not completed. There were 18 written comments. All scenarios completed were correctly scored. 4 key themes came out of the comments, **Table 5**.

**Table 5 – Themes that came out of the Scenarios comments**

<b>Theme</b>	<b>Example of comments</b>
Definitions and words used	Wording, some definitions can be confusing.
Thresh holds for using red section	Thresh hold for using the Red section, could be confusing for parents. The parents should call once they reach the amber stage.
Training/ education	Good clear training needed to used the CHAT2
Parental responses and	Parent's response boxes under amber can be confusing and need more explanation. Parents need clear advice about helpline numbers and what to do out



amber section	of hours.
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### **Scenarios/ simulation exercise – Worcester University – June 2017**

Kerry Gaskin at Worcester University hosted a scenario simulation with a range of invited stakeholders, including student nurses, ward nurses, cardiac nurse specialists. Parents were invited and expressed an interest but were unable to take part due childcare needs.

Six scenarios were used to trial CHAT2, four-telephone conversation and two parental preparation for discharge role play. After the exercise all participants met to verbally evaluate the experience and discuss findings.

The sessions were recorded by video in the simulation suite and written notes made. The overall feedback was very positive and resulted in a “really good way of testing CHAT2” as all involved were learning to use the tool at the same time as undertaking the clinical scenarios. Some of the other points raised were:

- Structure needed about how to use before discharge
- Discharge standard package needs to be developed
- Parents gradually take responsibility for the tool before discharge
- Other cares need to be introduced early, medications, red flags, signs and symptoms
- Laminate CHAT2
- Fold up credit card size
- A family day to be organised with Little Hearts Matter so parents can learn, use and practice using the CHAT2 and give their feedback.
- Use as part of documentation and clinical assessment

Overall this was a very successful, fun and well received day by all involved. It was an innovative way to learn for all involved. It provided excellent feedback and new ideas for the future App development.

### **CHAT2- Trial in the clinical setting**

Across the centres there were 12 potential infants and families clinically suitable for safe discharge home with CHAT2. Of the 12 infants, 6 could not use the CHAT2 due to psychosocial, understanding of CHAT2, or language

barriers, in that English was not their first language (**Table 6**). Of the 6 infants discharged using CHAT2, feedback was positive

**Table 6 – Family and infant characteristics**

<b>Demographic</b>		<b>Number HMP +CHAT2</b>	<b>Number No HMP or CHAT2</b>
<b>Ethnicity of child</b>			
<b>White</b>	<b>British</b>	<b>1</b>	<b>2</b>
	<b>European</b>	<b>3</b>	<b>1</b>
<b>Asian</b>	<b>Bangladeshi</b>	<b>1</b>	<b>1</b>
	<b>Pakistani</b>	<b>1</b>	<b>2</b>
	<b>Other</b>		
<b>Congenital Heart Disease</b>	<b>Shunt dependant physiology</b>	<b>2</b>	<b>3</b>
	<b>Single ventricle physiology</b>	<b>3</b>	<b>3</b>
	<b>Other</b>	<b>1</b>	
<b>Parental history</b>	<b>Psychosocial issues</b>	<b>2</b>	<b>1</b>
	<b>Understanding of training, use of CHAT2</b>		<b>1</b>
	<b>Language barrier/ understanding</b>	<b>1</b>	<b>1</b>

**Table 7 – Examples of CHAT2 triggers for families at home**

<b>Infant</b>	<b>Reason</b>	<b>Action</b>
<b>Red</b>	Unable to obtain oxygen saturations reading, hands and feet cool, a few “small vomits”. Infant quieter than usual. Not	Mother rang the CNS with information. As unable to feed taken to local hospital for review.

	interested in feeding.	
Red	Infant not well, not feeding, cold hands and feet, 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 over night. 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 CCNT possible reflux.	Taken into local for review of feeding and reflux issues. Assessed for dehydration and feeding tube passed.

CHAT2 had triggered correctly and was used effectively by the parent/ carer to raise concerns with the tertiary centre or the CCNT (**Table 7**). It was evident that the Amber triggers are usually action via consultation whilst the Red were usually reviewed by the team in retrospect the parents used their learning to action safe care of their infants rather than CHAT2. However it does provide a safety net and a resume. As yet we have not had feedback from a family focus group only individual quotes (**Table 8**)

**Table 8 – Quotes linked to use of CHAT2 in clinical setting**

Quotes	Parent/ carer
<i>"The CHAT2 tool was useful knowledge before I left hospital but on a daily basis I am not thinking are we on</i>	Parent (mother)

<i>green or amber. I ring ward or helpline if I have a question.”</i>	
<i>“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”.</i>	Parent (mother)
<i>“I had never acknowledged how precious the time was with my baby at home until my daughter had her second stage surgery.”</i>	Parent (mother)
<i>“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. ”</i>	Parent (mother)

The collaborative improvement team has demonstrated a high level of safe & effective use of CHAT2 using clinical records and scenarios, feedback from a wide range of staff groups and will continue to embed the CHAT2 into clinical practice as part of a HMP. As the clinical numbers were predicted to be small across the time frame of the study, the project plan to use other ways to simulate practical ways of demonstrating the CHAT2 use proved effective.

We were not able to achieve the time line predicted, but have achieved a greater depth and richness of understanding of the complexity of HMP in this patient group (**Table 9**). The group will continue to implement the time line work plan moving forward.

**Table 9 – Achievements**

Achieved	Comments
CHAT2	√
Case note reviews using CHAT2 (n=24)	√
Table top scenarios- paper/ electronic (n=52)	√
Simulation scenarios workshop with video (n=6)	√

Clinical Practice - Embedding CHAT2 within a Home Monitoring Programme (n=6)	√
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The feedback from the project teams shows an increasing understanding regarding the implementation of the CHAT2 as an early warning tool: setting the standard of safe care for infants with complex heart conditions at home.

**Table 11 – Quotes linked to the project team**

Quotes	Professional
<i>“it has been so rewarding working with the wider cardiac teams and being able to see the range of current practice and make sustainable and positive changes to our practice...incredibly useful to contact another centre for support and to be talking the same safety language.”</i>	Cardiac Nurse Specialist
<i>“to discharge the (baby) home was an incredible volume of work and communication. Not only did we have to train the family and family members but also decide how we would work with the local services to ensure (baby) remained safe and the lines of communication, escalation and information to the family were clear... talking to Dad on the first planned call was so rewarding for myself and for the Dad himself” ( baby gurgling in the back ground playing with sibling)</i>	Advanced nurse practitioner
<i>“first and foremost I want to know the infant is clinical well and safe prior to discharge home and that the family is aware of early signs and symptoms of deterioration and what to do next.”</i>	Medical team member
<i>“I am not a nurse, but it is good to see how clearly the plan of care can be laid out and understood by a wider team who may not know what to look out for. I like the colours, red, orange &amp; green. My own baby was not well and I know having clarity was so very important at that time of what to do and when and that I was always concerned I would miss something in his care.”</i>	Health Care Assistant
<i>“I have to say I like the CHAT2 tool, I think for a parent who is worried/ stressed it really simplifies things. I have always been a fan of the traffic light system as I think it makes things easier to understand. It gives the parents a clear this is who to speak to with different signs &amp; symptoms.”</i>	Staff nurse local district hospital

*(Words 1400 )*

### Part 3: Cost impact

The tariff for children's cardiac surgery is funded & paid for by NHS England Commissioning as cost per case and depends on the complexity of cardiac surgery undertaken. There is a surgical procedure cost and this is followed by a bed day cost, multiplied by the hospital length of stay. There is no income associated with discharge or discharge care between staged surgeries or for supporting a "virtual ward environment" for complex cardiac needs outside of the tertiary hospital.

As the survival rate of complex CHD has increased there has been no recognition of cost of community care to reduce risks including death. It appears there is mismatch between dramatic improvements in cardiac surgery survival and the associated costs of complex care needs post discharge to ensure effective use of resources with positive long term outcomes.

Once an infant is assessed as clinically safe for discharge home, this reduces bed day costs and frees a bed for other surgical infant needing specialist cardiac surgery. When clinical beds are at a premium and patient flow difficult to manage in the current NHS climate, every day an infant is safely at home, enables the bed to be utilised for another cardiac surgical case.

This current service provision is covered by commitment and dedication of the cardiac nurse specialist team who bring this patient group into their caseloads having implemented this new model of care for our most fragile cardiac infants and family support. Dr Medoff-Cooper at the Children's Hospital of Philadelphia is leading the REACH project to test effectiveness in a randomised controlled trial of Home Monitoring Programmes. Meanwhile many centres in the United Kingdom use charity funds to bridge this funding gap.

The funding of this collaborative project enabled clinically base staff to be involved with project work, learn new skills and work collaboratively which in turn had a significant effect on team work and quality of patient care by joint learning. The centres now contact each other for advice that was not previously accessible.

*"I was able to call another CNS team about our concerns regarding sending an infant home, which was not in agreement with the medical view. By talking to another cardiac team I felt confident with my decision as part of the Home Monitoring Programme. This infant stayed in the hospital setting and underwent earlier cardiac surgery. I am so please for this family that their (baby) is doing so well although currently remains on intensive care. I cannot express the confidence it gives me in keeping this infant and family safe."*  
Cardiac nurse specialist.

We did not have a health evaluation by a health economist and costing for this were not put into the project budget, but this model of care supports the NHS 5 year plan of keeping patients closer to home and working in partnership with parents/ carers.

In resume this model of care is largely unfunded going forward. The cost of putting in place a cardiac nurse specialist to develop a “virtual ward model” of Home Monitoring care would more than balanced out by the reduction in bed day costs (Table 3). The average cost of one of these infants stay in hospital is on average £40,000.

The future project should include a cost review.

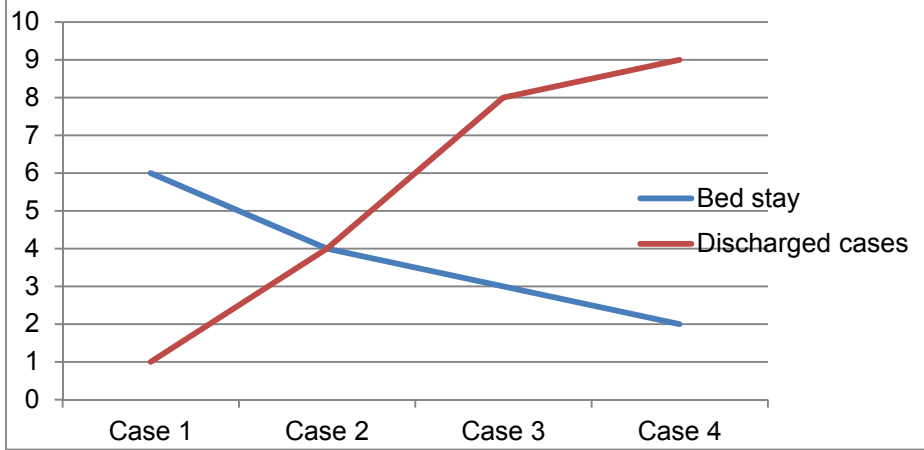
### Example of how it could be costed

Time line	Number
<p>Infant on home monitoring discharged home 2.8 weeks post surgery. Single ventricle physiology.</p> <p>Stayed at home for 3.2 months before next surgical pre-assessment. Family training in the Home Monitoring programme, weekly call by Cardiac Nurse Specialist and 3 weekly cardiology clinic attendance with consultant cardiologist.</p>	3.2 months = 96 days
2 red alerts CHAT2 with over night admissions to local hospital. Additional daily calls when admitted and initially discharge from the local hospital	5 calls
Weekly consultation calls from Cardiac Nurse Specialist.	15 calls
Admitted post MRI 3.2 months to confirm second stage cardiac surgery	1 day ward attendance preadmission
Discharged home post-surgery 15 days, Home Monitoring not required as circulation more robust and less affected by inter-current illness and fluid balance.	15 days in hospital

**Diagram 3 – Illustrating the inverse effect of increased discharge and Cardiac Nurse Specialist virtual ward case load and reduction in bed stay days and associated cost (not to scale, not actual costs)**



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Cases discharged & supported by cardiac nurse specialist

(Words 699)

## Part 4: Learning from your project

The project work was very positive regarding teamwork and the level of enthusiasm and the promoted learning. The teams were confident working across centres and engaging in dialogue. However collaborative working presented challenges not anticipated at the start. This was an underestimation of the increase in time for planning and executing multicentre meetings. For future similar studies we would budget in the costs regular telemedicine links. This would have helped mitigate some of the time and logistic issues the team faced.

As this is small group of patients the study design had planned to compensate for this by using table-top and clinical scenarios, however we were still influenced on clinical numbers by seasonal variability and underestimation of the impact of other reasons for parents/carers not being suitable for the Home Monitoring Programme. However this information was important to understand when supporting this patient group and has enriched our knowledge of this process by moving our sites to other professional engagement as we have not control over patient numbers.

Using the CHAT2 led to the recognition of the need for a structured assessment of parental/ carer suitability to enter the Home Monitoring Programme and a standardized education and training package. This additional development work has started but was not in the scope of this project.

These changes to the project time line along with “unforeseen delays” resulted in a delay in the predicted time line. When preparing a Gantt time line again, we would incorporate additional time for “unforeseen” and some additional time for delays and new developments along time line.

National events “unforeseen delays” cannot be ignored in 2017, with multiple terror attacks, which required the NHS to pool important specialist resources and a national cyber-attack, which affected not only the NHS internet structure but also the functioning and reliability of electronic communication.

The range of professionals and their diverse experience within the collaborative project team was very positive: nursing, health psychology, NHS, university staff and charity representation. This expanded our access to a wider range of resources, views and information across professionals, institutions and families.

During conferences having a twitter feed was very useful and a quick and effective communication resource, highlighting the importance of the rapid spread of information through electronic formats.

The teamwork developed stronger links between the centres in clinical practice. As an example the 4 centres contact each other to discuss individual cases and have formed a framework of support that was not previously accessible. This is an important support framework when pushing the boundaries of care and ensuring safety of the infant.

**Table 12 – Quotes linked to the project team**

Quote	Professional
<p><i>“its always good to phone a friend, knowing there is another team doing the same job means I can what are they doing about such and such, such I need a discharge proforma, this saves time ... we are all so busy and also sets a standard across the teams. “</i></p>	<p>Cardiac Nurse Specialist</p>
<p><i>“I was able to call another CNS team about our concerns regarding sending an infant home, which was not in agreement with the medical view. By talking to another cardiac team I felt confident with the decision as part of the Home Monitoring Programme. This infant stayed in the hospital setting and underwent earlier cardiac surgery. I am so please for this family that their (baby) is doing so well although currently remains on intensive care. I cannot express the confidence it gives me in keeping this infant and family safe.”</i></p>	<p>Cardiac nurse specialist.</p>
<p><i>“Until we started chatting I did not realise how much more (ideas are) available out there to look at and discuss it seems there are many different ways you can do something, such as delivering a programme of care.”</i></p>	<p>Cardiac Nurse Specialist</p>

The NHS five-year plan (2014) puts the empowering of patients and engaging with community services as a priority in new models of care. Projects such as this work that bridge inpatient and outpatient care are crucial to ensuring the first steps towards changing care models to meet the needs of our future infants and families in today’s challenging NHS climate.

The National Congenital Heart review is a key driver. The patient and family involvement groups from NHS England raised the inconsistency across services and the need to raise standardization by care bundles and pathways between different centres and across inpatient/outpatient care. The review also raises the importance of keeping care close to the patient and families home, which could be met in part with Home Monitoring Programmes.

The introduction of electronic records and wider electronic documentation at a

national level will be beneficial to communication across all care domains, but there still remains a significant lack of electronic connections between tertiary and primary care. An individual can carry a paper document, but there is no electronic record connection between the primary, and tertiary level of care at an electronic level, making 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.

The most unexpected challenge was the lack of understanding around the definition and implementation of an improvement project and research. The hospital trusts involved had a good understanding of quality improvement work and the collaborative improvement project was registered at each site. However for the University this was not possible as it only registers "research" and the documentation and paper work required for sign off was research based. This meant the project did not fit with the application. Although not resolved within a year the challenge was taken up the research department at Great Ormond Street Hospital to enable the work to continue, and resulted in precious time directed away from the core project work.

The diversity of ideas, acknowledgement and responses to CHAT2 were inspiring and interesting from professionals across the NHS. The drive especially by non specialist centres to use tools like the CHAT2 to bridge the gaps in knowledge between hospital and community based care was very evident. A new traffic light tool for triage of oncology patients in the shared care centres was published at the end of 2016, and it is not clear why it has not been implemented from the tertiary centre perspective.

There remains a significant gap in this type of EWT for community based / parental/carer needs in the community setting. This structure and format could be rolled out to other speciality groups with adaptations. This is one way to support safe and high quality care effectively.

In the current political and NHS climate of continuous reduction in funding, monetary funding is important to action new work, and explore new models of care to keep our patient and families as safe as possible. It was an immensely exciting opportunity to take ideas forward to clinical level.

(Words 1100)



## Part 5: Sustainability and spread

CHAT2 will continue to be embedded across the 4 centres continuing with the extended time line. CHAT2 has prompted development of a parental assessment for using the Home Monitoring Programme and a training and educational programme. The aim of the group is to seek further funding to support continued implementation across the national cardiac centres to replicate the benefits and engagement in this project work. This work stream will continue to support the increase in complex CHD survival and increased discharge into the community. The teams at the National Children's Cardiac Centres who care for this patient group already use a Home Monitoring Programme with support by the Cardiac Nurse Specialist and Cardiology teams.

- What (external) interest and recognition have you had on your innovation?
  - i. Have you received any awards, spoken at conferences, been published or had media interest?

Pediatricians with expertise in cardiology (PECs) were involved with discussions of the tool and delivered their views from the cardiac network

The group presented CHAT2 at the World Congress Paediatric Cardiology and Cardiac Surgery, Barcelona in July 2017, receiving interest especially from Australia, Brazil and across Europe. There was wide Twitter interest.

CHAT2 was presented at the British Congenital Cardiac Association, November 2017 with new opportunities for networking and meeting team members.

As the end of financial year approaches there have been initial meetings with the local commissioners for Commissioning for Quality & Innovation (CQUIN). This framework encourages care providers to share and continually improve how care is delivered and to achieve transparency and overall improvement in healthcare. The Univentricular CQUIN scheme, "requires the 10 Children's Cardiac Surgical Units in England formally to establish a home monitoring programme for all infants with univentricular circulations discharged from hospital prior to their superior cavopulmonary shunt procedure (called the "interstage" period). The interstage period is a high-risk time for this group of infants. Mortality during this time is up to 20%, somatic growth is slow and parental anxiety high." The aim of these early discussions is to add the CHAT2 tool into the CQUIN and expand the remit to support a wider infant group. This opportunity would also

support wider national engagement.

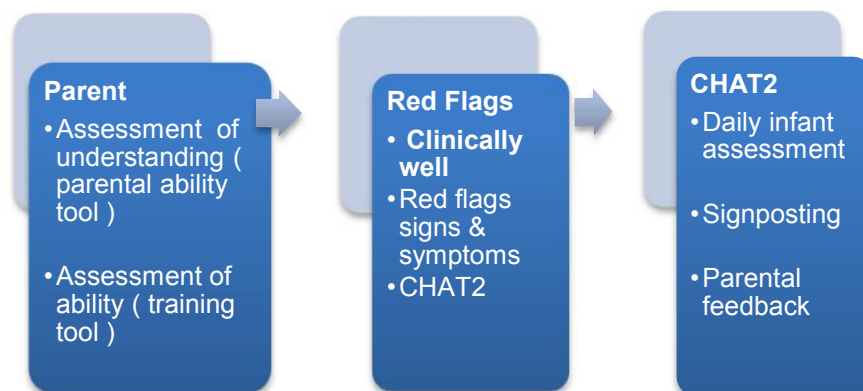
Local Rapid Response Lead Paediatricians for unexpected child deaths have joined an early dialogue regarding CHAT2 and the Home Monitoring Bundle. This is with an aim to try to understand if CHAT2 could support the framework of the meetings in the event of a death in this complex CHD.

The groups have engaged with the wider children's community services, with feedback from PECS, Community Children's Nurses, Health Visitors, nursing assistants. There has also been previous engagement with paramedics (Gaskin 2016).

Within the collaboration is a representative from the National Children's Cardiac Review and the group used the national standards already set to provide a framework for development. However the current framework lacks standards of care for these complex CHD infants especially around discharge home.

To disseminate to a wider international audience there will be a joint publication of this work, after the parental workshops are completed. It is hoped that this can be within a journal which can be accessed by primary care and specialist level staff.

#### Diagram 4 – The process moving forward



The CHAT2 has illustrated the importance of a process not just a programme. Highlighting the need for robust parental assessment, infant assessment, education around signs and symptoms (red flags) and the signposting needed for escalation of concerns (CHAT2), see Diagram 4.

**Table 10 – The future plans**

Going forward	Who/ how
Continue to embed the use of CHAT2	Current team
Expand use of CHAT2 to outside the project group.	New project team, grant monies sought
Work with other key players interested, community teams, paramedics	New project team, grant monies sought
Parental assessment for safe discharge	New project some work already undertaken, grant monies sought
Training & education programme	New project some work already undertaken, grant monies sought
Work the with standards implementation group for the National Children’s Cardiac Review for standardize care with CHAT2, around safe discharge	Current team
Costing of bed days savings	New project, grant monies sought
App development led by Dr Kerry Gaskin, Worcester University	Dr Kerry Gaskin & team

The project provided a trigger for renewed national working across the cardiac centres and a vision to re-establish national meetings based on achievements and to take a wider audience (**Table 11**). Due to the continued dedication and commitment from the cardiac nurse specialist teams the group is exploring funding to extend this work (**Table 10**) to achieve a national standardised bundle of care + CHAT2 for this patient group.

The collaborative group will continue to support their own centres work, but we are



seeking funding from other sources, with applications to the Burdett Nursing Trust and other innovative funding streams. In addition some centres have sought funding for new roles to support the Home Monitoring Programme from charitable funds such as the Well Child Trust. Dr Gaskin is leading a second grant application for an App development of CHAT2 with the charity Heart Research UK.

*(Words 820)*

## Appendix 1: Resources and appendices

Please attach any leaflets, posters, presentations, media coverage, blogs etc. you feel would be beneficial to share with others.


- Poster
- Presentation
- CHAT2
- Workshop feedback
- References

*Note that, as we would want to upload these onto the Health Foundation website, we ask that you are discerning with additional material provided.*

## Appendix 2: Project finance

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<b>Budget template</b>
See attached final budget.
<b>Commentary on variations to the budget</b>
Final budget attached with comments on variances. <ul style="list-style-type: none"><li>• One month over on pay cost balanced with final saving on non pay, resulting in the Final Budget coming in under.</li><li>• The budget line for design is currently unspent due to delays in design of the tool supported with feedback from parental focus groups. This has resulted in delayed design spend. Forecast to be spent in March 2018.</li><li>• Monies for the charity Little Heart Matters have not been spent due to delay in the parental workshops now forecast for February 2018.</li><li>• Any underspend will be used to complete the time line of the project over a longer time frame.</li></ul>

<b>Authorisation from finance department</b>	
Signed	
Name	TOM BURTON
Role	DEPUTY CFO

### Appendix 3: Feedback to the Health Foundation

**This is your opportunity to feedback to the Health Foundation about any aspect of your involvement in the Innovating for Improvement programme. We would welcome honest reflections on what worked and would could be better.**

There is no obligation to provide any comments but we would welcome your thoughts on:

- The learning events were extremely useful, setting the scene, networking, meeting support consultant, making new links, learning new information and skills. A productive way to start the project work and set the scene. The setting of the scene and hearing other teams was inspirational.
- The support consultant relationship was very important, and provided excellent support and direction. Jonathan G was very extremely professional, providing, support, direction, information and links to other people. It was good to have someone to contact and to link with the project work. The site visit was excellent and all information was of a very high standard and knowledge base. For example encouraging links with our hospitals transformation and improvement team.
- The Health Foundation team have all been very professional, easy to work with, reliable and helpful at all times. They have also been approachable and all the advice and support provided has been excellent.