

Preparing parents for discharge from hospital with their infant after complex cardiac surgery using the Congenital Heart Assessment Tool.

An online learning resource for health care professionals

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53 Annual Meeting
of the Association for
European Paediatric
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15-18 May 2019, Seville, Spain



2019

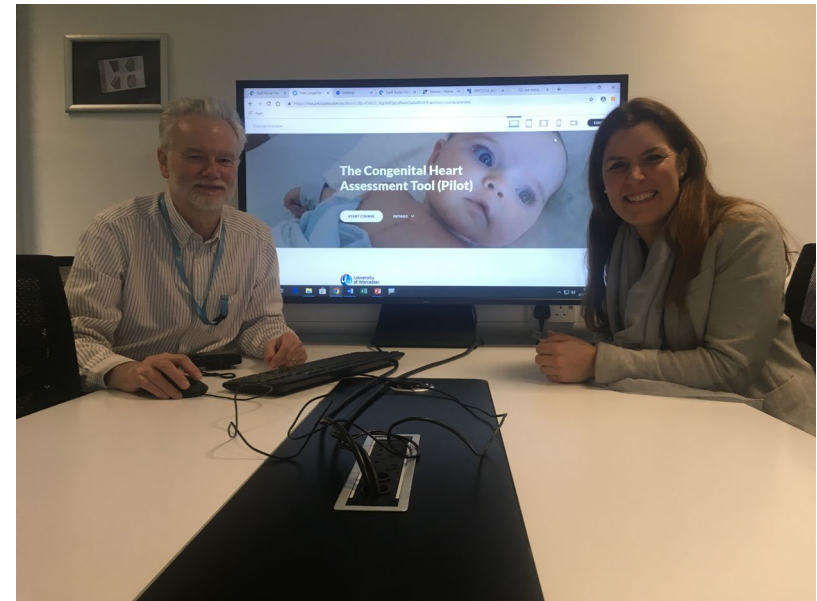
E-resource development - Acknowledgements

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Suzie Hutchinson, CEO, Little Hearts
Matter



Technology Enhanced Learning Unit,
TEL Me More Seminar [Video](#)



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Aim

The aim of this session is to present an online learning resource developed within a portfolio of research around the Congenital Heart Assessment Tool (CHAT).



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Background – Phase One

- CHAT, is an early warning tool for parents to use at home to monitor their infant following the first stage of surgery for complex Congenital Heart Disease (CHD)
- It was developed in 2012 and implemented within a feasibility Study (phase one) at one specialist centre during 2013-2015
- Gaskin K, Barron D and Daniels A (2016) Parents' preparedness for their infants' discharge following first-stage cardiac surgery: development of a parental early warning tool, *Cardiology in the Young*, 26(7):1414-1424
- Gaskin KL, Wray J, Barron DJ (2018) Acceptability of a parental early warning tool for parents of infants with complex congenital heart disease: a qualitative feasibility study *Archives of Disease in Childhood*, 103 (9):880-886



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Acknowledgements

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 - Funded the Research Nurse role (0.6WTE)
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 - Funded the purchase of equipment (pulse oximeters and digital scales)
- Sponsors, Coventry University (PhD)
- Patient & Public Involvement, Little Hearts Matter
- NIHR support through the Comprehensive Clinical Research Network



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Phase two

- To evaluate the CHAT in four children's cardiac centres in the UK
- Health Improvement Project during 2017 (Smith et al, 2018), resulting in an updated version of the tool (CHAT2).

Funding: The Health Foundation

Ethics Approval: University of Worcester Institute of Health & Society Ethics Committee

Evaluating an early warning tool

Setting the standard of safe care for infants with complex heart conditions at home

Authors

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Overview

CHAT2 was developed for parents/carers of infants with complex congenital heart disease, supporting assessment and decision making in the community setting. The key aim to improve the safety, quality of care & standardise decision making.

CHAT2 (Diagram 1)

CHAT2 uses a traffic light system **red** (emergency), **orange** (seek advice) & **green** (continue usual care). There are 6 domains:

- 1 Activity of infant
- 2 Skin colour and warmth
- 3 Breathing
- 4 Oxygen saturations
- 5 Feeding and nappies
- 6 Parental concern level – Parents/carers were assessed on their ability to use CHAT2 & received education within a Home Monitoring Programme (HMP) bundle. Parents/carers response to the parameters will be one of 3 levels of action, **green**, **orange** or **red**.

Parent/carers are taught to make a daily assessment of their infant or at any time their infant is not well (Gaskin 2016).

Community teams will use CHAT2 to support joint decision making (Tregay 2016).

‘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...’
– Parent of infant discharged home.

The problem (Diagram 2)

These infants have a higher risk of mortality between first & second stage surgery, called “interstage 1” due to their altered circulation at this stage of their surgical pathway. Early parental recognition & escalation of changes in an infants condition reduce mortality and morbidity risks.

Diagram 2. Patient pathways



Diagram 1. Congenital Heart Assessment Tool 2 (CHAT2)

Patient name:	Diagnosis:	Person calling:	Date:	Time:
Behaviour	<ul style="list-style-type: none"> Behaves normally e.g. content, smiles Stays awake or awakens quickly (as normal) Normal crying, easily soothed e.g. by feeding, comfort 	<ul style="list-style-type: none"> Quieter than usual Sleeping more than normal or less easy to settle Less responsive during normal activity Slightly irritable, unable to comfort 	<ul style="list-style-type: none"> 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 cry at all 	
Skin, colour and warmth	<ul style="list-style-type: none"> Your baby's usual colour of skin, tongue, especially lips and nails Your baby's usual warmth of hands and feet Normal body temperature between 36.5-37.2°C 	<ul style="list-style-type: none"> Blue tinge around mouth or finger tips, 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 	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Usual breathing rate and effort for your baby No cold symptoms, such as a runny nose 	<ul style="list-style-type: none"> More breathless, faster or slower breathing rate Has cold symptoms, runny nose, cough, noisier breathing than normal Snoring in skin below ribs or in the neck area more than normal Nasal flaring 	<ul style="list-style-type: none"> Not breathing or struggling to breath or exhausted – cannot cry Very noisy breathing, grunting or gasping Severe 'sucking in skin' below ribs or tracheal tug, head bobbing 	
Oxygen saturation	<ul style="list-style-type: none"> Oxygen saturation range normal for your baby (add individual's details) 70-75% oxygen saturation 	<ul style="list-style-type: none"> Oxygen saturation above or below the range for your baby on two consecutive readings 30 minutes apart 	<ul style="list-style-type: none"> If oxygen saturations constantly above or below the normal range for your baby If you are unable to obtain an oxygen saturation reading 	
Feeding and nappies	<ul style="list-style-type: none"> Baby feeding normally Regularly wet and dry nappies Wakes for feeds and is hungry No vomits, unless small possets are normal Weight increasing as expected (add individual's details) 	<ul style="list-style-type: none"> 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 dry with usual nappy changes Has not weight or weight unchanged or more weight increase than expected 	<ul style="list-style-type: none"> Vomiting or diarrhoea much more than normal (or twice in a row) Cannot feed Dry nappies for 4 hours or more Diarrhoea in nappy 	
Parent response	<ul style="list-style-type: none"> Parental carers happy with their baby 	<ul style="list-style-type: none"> Parents/carer concerned about their baby There may be no visible changes in the baby 	<ul style="list-style-type: none"> Extreme worry – baby very unwell / not breathing Parents start basic life support assessment 	
	<ul style="list-style-type: none"> Green on normal care 	<ul style="list-style-type: none"> Parents to contact cardiac nurse specialist ward 	<ul style="list-style-type: none"> Advise to contact cardiac nurse specialist team 	<ul style="list-style-type: none"> Advise to attend local hospital
			<ul style="list-style-type: none"> Advise parents to call 999 straight away 	

‘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 discharged home.

Results (Table 1 & 2)

CHAT2 triggered correctly in all the scenarios. Feedback from groups & experts provided a cycle of improvement & real time changes using a PDSA cycle. Parents/carers who used CHAT2 in the clinical setting within their HMP team found CHAT2 supported decision making & signposting.

Table 1. CHAT2 triggers parents at home

Infant alert	Reason	Action
Amber	Weight loss no weight gain	Called by community team, admitted to local for feeding review & early cardiology review
Red	Unable to obtain oxygen saturations reading, hands and feet cool, slow 'small vomits' - faster quieter than usual, Not feeding.	Mother rang the CNS with information from local hospital. Arrived to be fed, concerned & had taken infant to local hospital for assessment: discussion, Local and tertiary hospital.

Table 2. Interventions

Intervention	Addressed	Comments
CHAT2	Not review	PDSA cycles
Case note	n=24	Adding CHAT2 to case notes
Table top scenarios	n=52	Paper & electronic
Simulations & video	n=6	Cardiac triage
Clinical setting with a HMP bundle	n=6	Worcester University, videoed CHAT2 + HMP
Parent/carer and community issues	PENDING	Focus groups, Feedback, individual interviews

Next steps

- family focus groups & individual interviews
- development of a parental/carer assessment tool for capacity to partake in a HMP
- development of a parent/carer educational package
- standardized care using CHAT2 role out to other centres
- app development (Worcester University)

Lessons learnt

- collaborative learning and working
- the power of teamwork
- complexity of standardizing care bundles
- time expectations for collaborative work

Acknowledgements

THF Project Lead: Liz Smith, Lead Nurse, Cardiac Unit; Great Ormond Street Hospital for Children, London

Principal Investigator for Clinical Simulation and Parent Workshops: Dr Kerry Gaskin, Principal Lecturer, University of Worcester

Participants Clinical Simulation Exercise: – Amanda Daniels, Associate Lecturer; Ben Pickering, Mel Carpenter, Victoria Reynolds, Students Children’s Nursing, University of Worcester; Suzie Hutchinson, Chief Executive, Little Hearts Matter; Debra Rutter & Debbie Lawson, Cardiac Nurse Specialists, Children’s Cardiac Unit, Freeman Hospital, Newcastle upon Tyne

THF Project Collaborators: - Dr Jo Wray, Senior Research Fellow – Health Psychology; Dr Kate Brown, Consultant Intensivist, Great Ormond Street Hospital for Children, London; Justine Kidd & Kay Dyer, Cardiac Nurse Specialists, Cardiac Unit, Birmingham Children’s Hospital; Dr Anna Seale, Consultant Fetal Cardiologist, Mr David Barron, Consultant Cardiac Surgeon, Cardiac Unit, Birmingham Children’s Hospital; Collette Cochran & Gill Harte, Cardiac Nurse Specialists, Children’s Cardiac Unit, Southampton General Hospital

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

Great Ormond Street Hospital for Children
NHS Foundation Trust

University Hospital Southampton
NHS Foundation Trust

Dr Kerry Gaskin
University of Worcester



The Newcastle upon Tyne Hospitals
NHS Foundation Trust

NHS Birmingham Women's and Children's
NHS Foundation Trust

Little Hearts Matter
Help a heart, not a life

The Aim

The aim of the collaborative improvement project is to implement in the clinical setting the CHAT 2 Early Warning Tool for infants with complex congenital heart disease home across 4 national cardiac children's centres. The tool is expected to be part of a bundle of care for a national home monitoring programme (HMP), including a training and education programme. The tool will support decision making by families and children's community teams to improve safety, quality of care and standardize care provision.

Evaluation

- Organisation of key domains into mutually agreed visual formatted tool
- focus group work with parents and stakeholders acceptability to families, understanding of the tool
- trial of the tool using retrospective clinical record review
- scenario based (table top) with stakeholders and clinical experts
- correctly triggers with escalation plan in the clinical setting within local HMP bundle

Progress to date

- Standardizing & review of the HMP at each centre
- Review of tool and discussion against national guidelines
- Scenarios to trial tool across professional groups
- Clinical simulation scenario (Worcester)-very positive event using telephone consultation & discharge preparation. Outcomes included training time & package for tool use, changes to the tool layout, how would it sit in the discharge bundle

Planned

- Focus & feedback work with parents - acceptability, design, training & education support plan, understanding of words used (Little Heart Matters)

Background

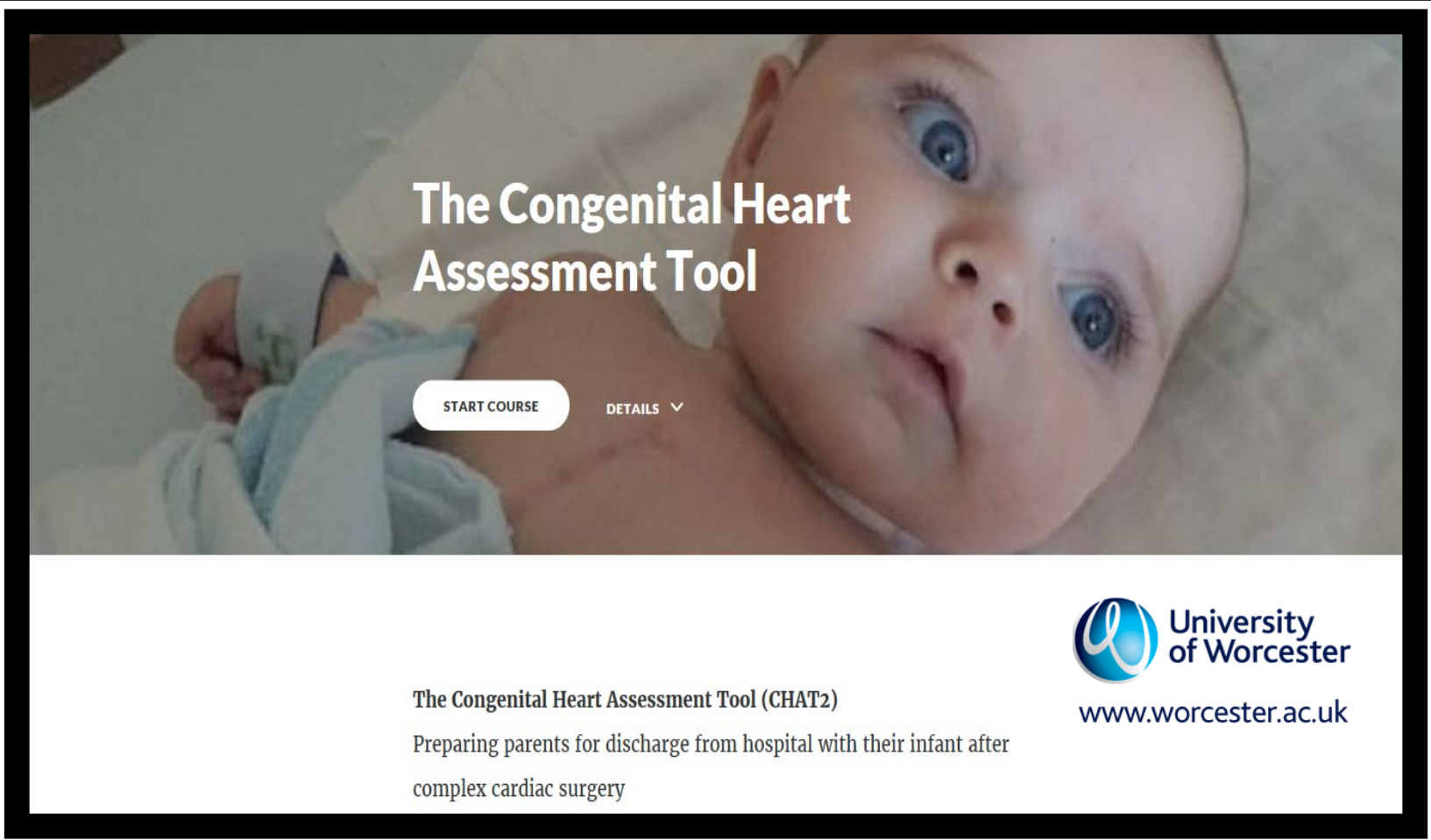
Congenital heart disease (CHD) affects 71000 UK live births (Knowles 2005). National CHD data shows there were 888 operations/interventions in the neonatal group (CCAD 2016), with 30 day survival of 98.2%. ~150 infants a year have extremely complex CHD associated with the highest risk of mortality and morbidity Home Monitoring Programs (HMP) have been shown to reduce the risk of mortality & morbidity in this group (Ghanayem 2004, Gardini 2015) and there is evidence of the vigilance of families / carers in optimising the outcome of infants in the first year of life (Rempel, 2012, Gaskin 2016).

Parent Name	Diagnosis	Non-caring	Site	Time
Congenital Heart Assessment Tool CHAT 2 HCP version				
Behavior	<ul style="list-style-type: none"> • Relaxed, calm and in control • Eye contact and awareness of the infant • Non-feeding, baby, watching in feeding position 	<ul style="list-style-type: none"> • Cuddles the infant • Feeding position that causes stress, weight falls • Less responsive to infant's activity • Slightly irritable, irritable or crying at 4 	<ul style="list-style-type: none"> • Not responding to usual interventions • Distress or irritability if touched, does not settle easily • Rash or spots • Right/irritated or combative/crying or crying at 4 	
Bin Color	<ul style="list-style-type: none"> • The infant is awake/alert with pink, rosy lips • The infant is not flushed or red • Normal/normal temperature between 36.0 - 37.5°C 	<ul style="list-style-type: none"> • Background sound muffled or higher than pale/floored or skin is red/dull • Dry/cracked or cracked lips and feet/feet are cool • Temperature non-feet 37.1 - 38.0°C or below 36.0°C 	<ul style="list-style-type: none"> • Not settled, pale, blue or grey skin • Irritable, restless or crying • Very pale lips, hands, feet or limbs • Irritability not well • Temperature non-feet 38°C 	
Breathing	<ul style="list-style-type: none"> • Normal breathing rate and effort for your baby • Normal respiratory sounds in lung area 	<ul style="list-style-type: none"> • Slow breathing, faster or slower breathing rate • Fast respiratory sounds, cough, wheezing, stridor • Sucking on your breast or at a breast, slow non-normal • Nasal flaring 	<ul style="list-style-type: none"> • Not breathing or struggling to breathe or distressed • Coughed on • Very noisy breathing, grunting or popping sounds, feeding or not well, blue or a swollen leg, hand/feet 	
Oxygen saturation	<ul style="list-style-type: none"> • Oxygen saturation target according to your baby • All red/pink areas • 92-95% Oxygen saturation 	<ul style="list-style-type: none"> • Oxygen saturation above or below the target for your baby • All noticeable readings 2 minutes apart 	<ul style="list-style-type: none"> • Oxygen saturation consistently above or below the normal range for your baby • Or you are unable to take an oxygen saturation reading 	
Feeding	<ul style="list-style-type: none"> • Baby feeding normally • Regularly wetted nappies • Wakes to feed and is hungry • Feeds well, when and how you want • Weight continues to increase • All red/pink 	<ul style="list-style-type: none"> • Any abnormal vomiting, including projectile • Irritability and crying, feeding, poor • Struggling to feed, taking longer to feed, breathless or feeding or unable to sleep • Irritability and crying with usual sleep changes • Has noticeable weight and/or height increase that is expected 	<ul style="list-style-type: none"> • Vomiting or diarrhoeal stools/constipation • Crying at a feed • Crying feed • Dry nappies for 4 hours or more • Poor weight gain 	
Parent response	<ul style="list-style-type: none"> • Parents seem happy with their baby • They require no advice about their baby • They require no advice about their baby 	<ul style="list-style-type: none"> • Parents seem concerned about their baby • They require no advice about their baby • They require no advice about their baby 	<ul style="list-style-type: none"> • Distress or irritability, very unsettled/feeding • Parents don't feel they are coping 	

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Phase three- Develop e-resource



The Congenital Heart Assessment Tool

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The Congenital Heart Assessment Tool (CHAT2)
Preparing parents for discharge from hospital with their infant after complex cardiac surgery

Funding: University of Worcester Learning, Teaching and Student Experience Project
Fun 2017/18



Features

- Entirely online
- User friendly, accessible, flexible
- Video footage to support learning
- Audio and written format to support different learning styles
- Learn to assess six key symptoms using the CHAT2
- Activities: customise your own learning
- Resources section: guide to other learning resources
- Professional Development Certificate on completion

Demonstrate e-resource



Learning Outcomes

1. To enable health care professionals (HCP) looking after infants with complex congenital heart disease (CHD) to learn about the Congenital Heart Assessment Tool [version 2] (CHAT2) and to explore the underpinning evidence supporting its development
2. To reflect upon aetiology, epidemiology and incidence of complex CHD; the anatomy and pathophysiology of complex CHD and the staged surgical approach to enhance own knowledge and understanding
3. To enable HCPs to teach parents about the signs and symptoms of clinical deterioration they need to look out for in their infant, between stages one and two of surgery



Learning Outcome 4

Enable HCPs to teach parents how to use the Congenital Heart Assessment Tool (CHAT2) to identify changes in their infant's condition





Learning Outcome 5

Enable HCPs to use the Congenital Heart Assessment Tool (CHAT2) to support decision making about management strategies when contacted by parents

Behaviour	<ul style="list-style-type: none"><input type="checkbox"/> Quieter than usual<input type="checkbox"/> Sleeping more than normal or less easy to settle<input type="checkbox"/> Less responsive during normal activity<input type="checkbox"/> Slightly irritable, unable to comfort
Skin Colour	<ul style="list-style-type: none"><input type="checkbox"/> Blue tinge around mouth or finger tips, paler than usual, or skin is mottled
Warmth	<ul style="list-style-type: none"><input type="checkbox"/> Sweaty skin or cooler hands and feet than usual<input type="checkbox"/> 'Soft spot' feels different to normal<input type="checkbox"/> Temperature more than 37.5 - 38 °C or below 36 °C
Breathing	<ul style="list-style-type: none"><input type="checkbox"/> More breathless, faster or slower breathing rate<input type="checkbox"/> Has cold symptoms, runny nose, cough, noisier breathing than normal<input type="checkbox"/> Scaking in skin below ribs or in the lower front neck area, more than normal<input type="checkbox"/> Nasal flaring (nostrils become wider as baby breathes)
Oxygen saturation	<ul style="list-style-type: none"><input type="checkbox"/> Oxygen saturation above or below the range for your baby on two separate readings, repeated 30 minutes apart
Feeding Nappies	<ul style="list-style-type: none"><input type="checkbox"/> Any diarrhoea or vomiting, including vomit after medications or not sleeping feeds down<input type="checkbox"/> Struggling to feed, taking longer to feed, breathless on feeding, or sweaty during feeding<input type="checkbox"/> Nappies not wet or dirty (change from usual nappy change times)<input type="checkbox"/> Has lost weight or weight unchanged or more weight increase than expected
Parent response	<ul style="list-style-type: none"><input type="checkbox"/> Parents / carer concerned about their baby<input type="checkbox"/> There may be no visible changes in the baby condition
Contact for Advice:	
Cardiac Ward (evening/night/weekend/bank holidays)	
Tel: _____	
Cardiac Nurse Specialist Team (9.5am)	
Tel: _____	

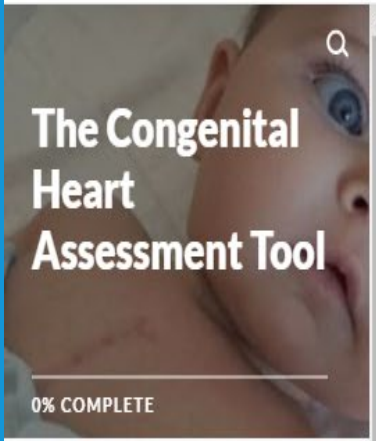


EDIT

The Congenital Heart Assessment Tool

START COURSE

DETAILS ▾



The Congenital Heart Assessment Tool

0% COMPLETE



Lesson 1 of 10

Implementation of CHAT

Implementation of CHAT

CHAT Introduction

CHAT Learning Outcome 1

CHAT Learning Outcome 2

CHAT Learning Outcome 3



Registering your interest

If you are the Lead Nurse or Lead Consultant for the Network (or Cardiac Unit) and are considering implementing CHAT as part of your discharge process for infants following

The Congenital Heart Assessment Tool

0% COMPLETE

- Implementation of CHAT
- CHAT Introduction**
- CHAT Learning Outcome 1
- CHAT Learning Outcome 2
- CHAT Learning Outcome 3



Before You Start

Find a pen and a notebook so that you can make notes and complete the activities. You will need to turn on the speakers on your device to listen to the audio and video clips. If you are in a public place viewing this on your phone or tablet you may like to use earphones! You will be able to stop and start this e-resource whenever you like and come back to it at a convenient time. You don't have to complete it all in one attempt.

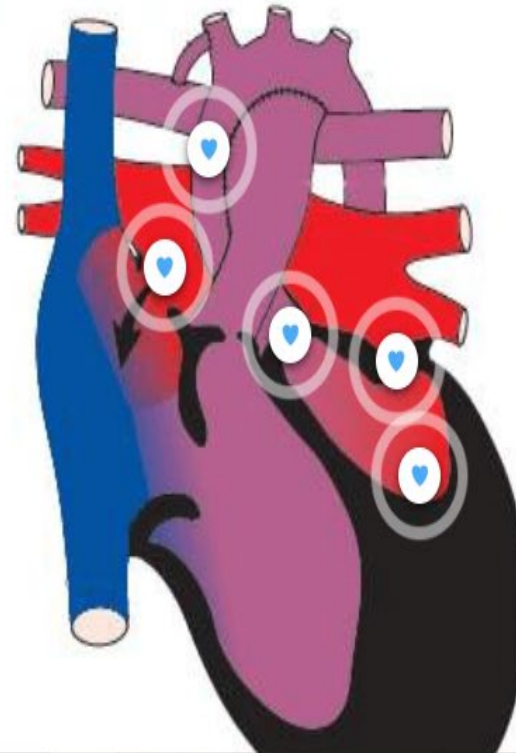
The Congenital Heart Assessment Tool

0% COMPLETE

- Implementation of CHAT
- CHAT Introduction
- CHAT Learning Outcome 1
- CHAT Learning Outcome 2
- CHAT Learning Outcome 3

Hypoplastic Left Heart Syndrome

Hypoplastic Left Heart Syndrome is a congenital heart condition (a problem that a baby is born with). Below is a description of the heart condition and possible treatments offered





The Congenital Heart Assessment Tool

0% COMPLETE

- Implementation of CHAT
- CHAT Introduction
- CHAT Learning Outcome 1
- CHAT Learning Outcome 2
- CHAT Learning Outcome 3



Develop an understanding of the CHAT, who is it for, what it does and why is it used?

Parents are taught using an early warning tool called CHAT, to assess their infant's activity level, skin colour, breathing, circulation, feeding and weight and to decide actions based on the information in each of the three columns (green, amber and red). The CHAT is based on a traffic light system:

- green (low risk). parents can 'carry on as normal'



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Thank you

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Half a heart...not half a life

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