

# Acceptability of a Parental Early Warning Tool Outcomes from a Feasibility Study of Parental Home Monitoring and Assessment

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## Background

Home monitoring programmes (HMP) were developed to encourage early recognition of deterioration in infants who are at risk of potentially life threatening events between the first and second surgical stage and focus on parents obtaining daily measurements of their infant's oxygen saturations (SpO<sub>2</sub>) and weight (wt.). In this study, the role of a Congenital Heart Assessment Tool (CHAT), was assessed as an additional part of the HMP package. The CHAT was designed for ease of use and incorporated a traffic light system enabling parents to assess the severity of their infant's condition through individualised parameters. *Green* assessment directed parents to 'carry on as normal'; *amber* triggered a phone call to the ward to discuss management; a *red* response, indicated the infant was seriously ill and parents were advised to phone for an ambulance immediately.

## Aim

The principle aim was to explore the feasibility of a Congenital Heart Assessment Tool (CHAT) (see table 4) as part of a home monitoring programme (HMP) for parents going home with their infant between the first and second stage of surgery for complex congenital heart disease, including single ventricle and systemic shunt dependent conditions. This paper also reports on how many times parents made urgent contact with health care professionals (HCP) (see table 3) and the acceptability of the CHAT and HMP from the parents' perspective, emerging from interviews with parents (see table 2)

## Method

A mixed methods approach was adopted. Data was collected at four time points: at discharge [T0]; 2 weeks after discharge [T1], 8 weeks after [T2] and after stage two surgery [T3] using self-report tools, semi-structured interviews and daily diaries. Parents were recruited between August 2013 and February 2015. After obtaining consent parents were randomised into one of three groups: Group A, measured SpO<sub>2</sub> and wt. daily and assessed their infant daily using the CHAT; Group B, used the CHAT alone or Group C, received standard discharge care. Participation ended when their infant returned for stage 2 cardiac surgery. 13 families were recruited (see table 1)

Recruitment (hospital survivors)	
Screened	66
Ineligible	19
Refused	15
Missed	19
<b>Recruited</b>	<b>13</b>

	Interviews with Mothers (n, %)	Interviews with Fathers (n, %)
T0	12 (92%)	4 (100%)
T1	9 (69%)	4 (100%)
T2	7 (54%)	3 (75%)
T3	9 (69%)	2 (50%)

Group	(n)	CHAT Amber (n)	CHAT Red (n)	Contact with HCPs
A	5	1	1	3
B	4	6	0	7
C	4	NA	NA	5

Table 1. Recruitment

Table 2. Number of Interviews

Table 3. CHAT Triggers & contact with HCPs

## Contact with HCPs

- There were no interstage deaths amongst the entire patient group
- In total 15 contacts were made with HCPs by parents, in all three groups (see table 3).
- Both the CHAT and HMP were helpful in triggering contacts; mostly related to respiratory signs, rather than a primary cardiac problem
- One Red CHAT triggered an emergency admission to the local hospital, infant JT8 was discharged the next day
- JT8 red trigger was based on CHAT warning signs and corresponding O<sub>2</sub> saturation changes (Figures 1-2)
- Amber CHAT trigger for NK4 and corresponding HMP can be seen in Figures 3-4
- These two infants JT8 and NK4 were admitted for further surgical interventions following scheduled appointments at the hospital and not relating to a CHAT/HMP trigger
- Two of the families in Group A did not record any of the daily measurements and did not return the daily diaries
- One mother in group B contacted HCPs for advice based on her own perceptions of her infant's condition rather than using the CHAT, as the CHAT had given her the confidence to know what was normal for her infant

Figure 1 and 2 JT8 Group A, Red CHAT Red Trigger and HMP measurements

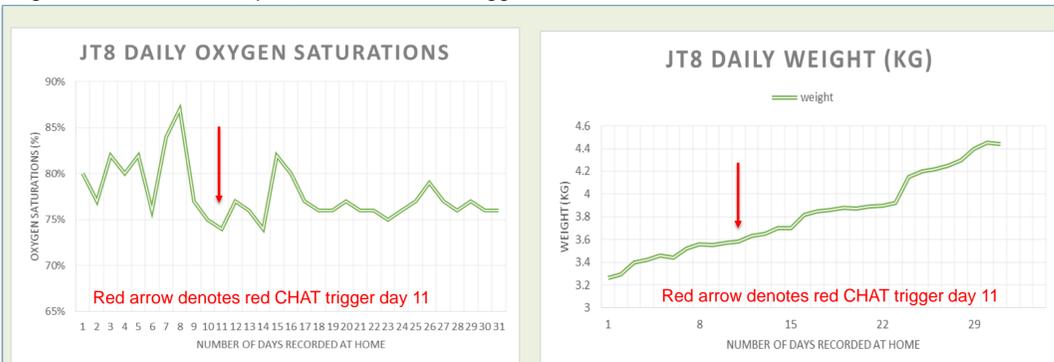
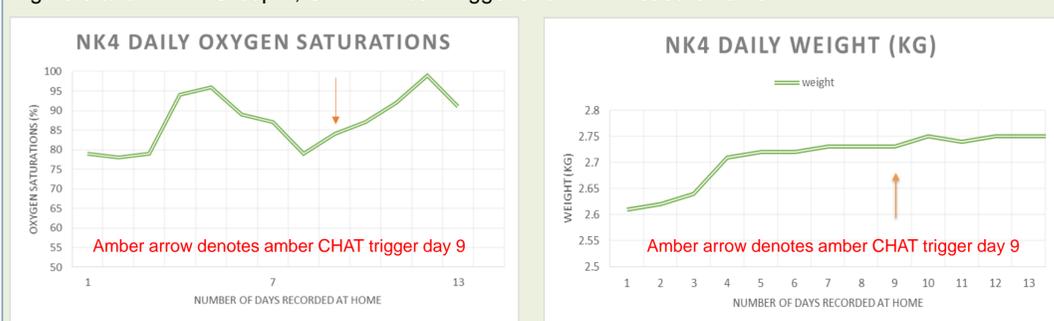


Figure 3 and 4 NK4 Group A, CHAT Amber Trigger and HMP measurements



Parent's TLS	Green – low risk	Amber – Intermediate Risk	Red- High Risk
Parent's TLS		A – if any of these signs are present ring for advice from Ward 11 – if in doubt call 999	R – if any of these signs are present ring 999
Baby's Skin Colour	Your baby's usual colour of skin, tongue, especially lips and nails	Bluer or paler than usual, or mottled	Very pale/bluer, very mottled
Baby's Activity	Behaves normally e.g. Content/smiles  Stays awake or awakens quickly (as normal)  Normal crying easily resolved by e.g. feeding, comfort, nappy change etc	Quieter than normal, not feeding as normal  Sleeping more than normal  Responding less during normal activity  Slightly irritable	Not responding to normal activity  Does not wake or if roused does not stay awake  Weak, high-pitched or continuous cry or no crying at all
Baby's breathing	Usual breathing (rate, rhythm and effort) for your baby	More breathless, faster rate, working harder to breath, noisier breathing than normal  Sucking in skin below ribs more than normal  Nasal flaring  Oxygen saturation range (add individual details ) .....	• Very breathless • Struggling to breath • Exhausted • Very noisy breathing (Grunting) • Very fast breathing or very slow breathing • severe 'sucking in skin' below ribs
Baby's circulation	Your baby's usual colour and warmth of hands and feet	More sweaty or clammy than usual Cooler hands and feet than usual and not 'pinking back up' Eyes, hand, feet and/or tummy puffed/more	Very cold, sweaty or clammy hands and feet Unresponsive Very puffy/ very swollen eyes, hands, feet or tummy

Table 4. An extract of the CHAT

## Parents' perceptions - HMP

Two key themes emerged from the interviews with Group A parents:

1. Parents were worried about becoming reliant on the equipment (before discharge)
  2. Parents did not follow the HMP strictly on a daily basis
- Parents used the oxygen saturation monitor when they were worried as it was 'more reassuring than the scales'
  - The scales were 'a hindrance more than helpful'; weighing became 'a chore and a burden, especially when they were getting behind with other aspects of their infant's care'

## Parents perceptions - CHAT

Four key themes emerged from the interviews with Group A and B parents about their perceptions of the CHAT:

1. Had prepared them for the signs that they needed to look out for at home
2. Was easy to use
3. Had increased their confidence
4. Gave them reassurance to call for advice when they noticed that something was different

## Conclusions

The CHAT is a valuable addition to HMPs and gives parents greater confidence and reassurance in monitoring their child. There were zero interstage deaths in the study. Both the CHAT and the standard HMP stimulated contact with HCPs. However, three families in group A who took part in the interviews (table 2) found the weighing scales unhelpful. One mother in group B described how she sought HCP advice independently of the CHAT, after developing confidence through use of the CHAT in the early days of being at home.

## Limitations

Small recruitment numbers made statistical comparison difficult. Language barriers were an obstacle to recruitment and need to be considered for future studies. Some parents were offered monitoring via community teams as standard discharge care, therefore did not feel the need to take part in the study. There was a lack of consistent documentation recorded by ward staff following contact with parents for CHAT triggers; and incomplete data recorded by group A and B parents in their diaries

## Affiliations:

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