Supplementary File 3:

**Nutritional pathway for Infants with congenital heart disease before surgery**

Using Steps 1 – 5 assess nutrition risk, classify growth, consider how and what an infant is drinking and eating to determine which nutrition care plan is appropriate e.g. A, B or C.

<table>
<thead>
<tr>
<th><strong>Patient Assessment Sheet: Nutrition &amp; Feeding Skills</strong></th>
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<td>1. Assess CHD nutrition risk</td>
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<td>2. Assess and classify infant’s growth</td>
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<td>3. How does the infant eat and drink?</td>
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<td>4. What does the infant eat and drink?</td>
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<td>5. Chose a Nutrition care plan</td>
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<tr>
<td>A</td>
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<td>B</td>
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<td>C</td>
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<td>6. Exit criteria</td>
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<tr>
<td>Dietetics</td>
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<td>SLT</td>
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STEP 1 Assess and classify the infant with CHD nutritional needs

Key message 1
The nutritional needs of infants with CHD will depend on the type of cardiac lesion

<table>
<thead>
<tr>
<th>Lower nutrition risk*</th>
<th>Higher nutrition risk*</th>
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<tbody>
<tr>
<td>• Patent ductus arteriosus – (if early surgery)</td>
<td>• Pulmonary atresia</td>
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<tr>
<td>• Atrial septal defect</td>
<td>• Prostin dependent lesion</td>
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<tr>
<td>• Cor triatriatum</td>
<td>• Tetralogy of Fallot</td>
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<tr>
<td>• Total anomalous pulmonary venous drainage</td>
<td>• Atrial septal defect – (severe lesion)</td>
</tr>
<tr>
<td>• Pulmonary stenosis</td>
<td>• Ventricular septal defect – (moderate to large)</td>
</tr>
<tr>
<td>• Transposition of great arteries</td>
<td>• Arterioventricular septal defect</td>
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<tr>
<td>• Coarctation of aorta</td>
<td>• Hypoplastic left heart syndrome</td>
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*This is not an exhaustive list and does not replace clinical judgement with respect to nutrition risk

Notes:
- Nutrition risk will be higher in infants with more than 1 cardiac lesion congenital or chromosomal abnormality such as: T21/18/13/MVACTRL/ CHARGE/ Gastrointestinal atresia/ Congenital chylothorax/ Severe cardiomyopathy/ Syndromes: Noonan / Turners / Williams/ Di-George
- Premature infants or those with intra uterine growth retardation / absent or reversed end diastolic flow

STEP 2 Assess and classify the infants growth

Key message 2
Regularly plotting weight, length and head circumference on an appropriate growth chart in infants with CHD provides the opportunity to intervene where there are signs of growth faltering.

<table>
<thead>
<tr>
<th>Lower nutritional risk</th>
<th>Higher nutritional risk</th>
</tr>
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<tbody>
<tr>
<td>• Gaining adequate amounts of weight e.g. approx. 10g/kg/day and length ≈ 2cm per month</td>
<td>• Failure to gain adequate amounts of weight &lt; 10g/kg /day and &lt;2cm per month</td>
</tr>
<tr>
<td>• Weight/ length not more than 2 centiles below birth centile</td>
<td>• Sustained weight/ length drop of more 2 centiles or more from birth after 3 weeks of age</td>
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<tr>
<td>• Following a growth curve which is not more than 2 centiles below birth centile</td>
<td>• Flattening growth curve or is dropping downwards e.g. losing weight</td>
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STEP 3 How does the infant eat or drink?

Key message 3:
Prevent oral aversion by referring and involving a SLT early to assess feeding skills, particularly where there is a lack of progress or regression of feeding skills and associated clinical signs e.g. coughing, gagging or choking with feeds

STEP 4 What and how much does the infant eat and drink?

Key message 4:
Restricted feed or food intake may impact on the infant’s ability to maintain adequate nutritional status
Step 5 CHOOSING A NUTRITION CARE PLAN: A, B or C:
At each review using the flow diagram below decide the appropriate care plan outlined in the tables that follow

**Plan A:**
An infant will be:
- Growing well e.g. on a growth chart tracking upwards & not more than 1 centile below birth centile for weight/length/HC
- Able to meet nutritional requirements orally e.g. bottle or breast feeding

**Plan B:**
An infant will be:
- Not growing well e.g. between 1-2 centile below birth centile for weight/length/HC
- Have a CHD lesion with a higher nutrition risk but drinks well
- Finishes > 75% of feeds orally
- Fluid intake <120ml/kg/ day

**Plan C:**
An infant will be:
- Not growing e.g. > 2 centile below birth centile for weight/length/HC
- Have a CHD lesion with a higher nutrition risk but no oral feeds
- Requires NGT/NJT for feeding
- Fluid intake <100ml/kg/day

**Continue on Plan A:**
Local team to monitor growth/feeding progress

**Continue on Plan B:**
Review every 2 weeks
- Step 2: Growth - using an appropriate chart
- Step 3: How an infant is eating or drinking
- Step 4: What & how much is eaten or drunk

**Continue on Plan C:**
Review every week
- Step 2: Growth - using an appropriate chart
- Step 3: How an infant is eating or drinking
- Step 4: What & how much is eaten or drunk
### STEP 5  **CHOOSE A NUTRITION CARE PLAN - A, B OR C**

**Key message 5:** Involve a Paediatric Dietitian and Speech & Language Therapist in developing a nutritional and feeding care plan for an infant requiring plan B or C

<table>
<thead>
<tr>
<th>Care Plan</th>
<th>Nutritional and feeding care plan</th>
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| **A**     | • Normal energy and protein requirements* 90 - 100kcal/kg protein 1.5/kg (e.g. 2g protein per 150ml)  
• Normal fluid allowance e.g. 150ml/kg or above  
• Breastfeeding or standard infant formula on demand  
• Complementary food from 17 – 26 weeks if ready – 3 small meals/ day. Starches should form the basis of all meals, including veg/fruit. Offer protein containing meals (chicken/ fish/ meat/ eggs/ pulses) at lunch / supper.  
• Vitamins supplement to provide up to 10µg vitamin D  
• Review by local team – refer to specialist centre with any concerns |
| **B**     | • Approximately 10% extra energy* 100 – 110kcal/kg (protein contributing 9 -12% energy)  
• Approximately 30 - 50% extra protein* (around 2.5g/kg protein)  
• Breastmilk or standard infant formula in addition to 30 -80% of nutrition requirements from nutrient dense infant formula per day  
• Complementary food from 17 – 26 weeks of age if ready – 3 small meals/ day. Starches should form the basis of all meals, including veg/fruit. Offer protein containing meals (chicken/ fish/ meat/ eggs/ pulses) at lunch / supper. Around 6 months of age add ½ - 1 teaspoon of a nut butter or finely ground nuts to both main meals  
• Vitamin supplement daily to provide up to 10µg vitamin D  
• If there are any feeding issues refer to SLT  
• Paediatric dietetic review growth in 2 weeks – if poor weight gain review earlier & move to plan C |
| **C**     | • May be fluid restricted  
• Approximately 10 - 20% extra energy* 120 - 150kcal/kg (protein contributing 10 -15% energy)  
• Approximately 50 - 100% extra protein (up to 4g/kg protein – check renal function)  
• Breastmilk or standard infant formula in addition to a minimum of 50 and up to 100% of nutrition requirements as energy/ nutrient dense infant formula or as overnight or nasogastric feeds  
• Complementary food from 17 – 26 weeks of age if ready – 3 small meals/ day. Starches should form the basis of all meals, including veg/fruit. Offer protein containing meals (chicken/ fish/ meat/ eggs/ pulses) at lunch/ supper. Around 6 months of age add 1 - 2 teaspoon of a nut butter or finely ground nuts all meals  
• Vitamin supplement daily to provide up to 10µg vitamin D  
• If there are any feeding issues refer to SLT  
• Paediatric dietetic review of growth in 1 week |

### STEP 6: Exit criteria for dietetic & SLT support

| Dietetics | Post - operatively it may take 12 weeks or more for sufficient catch up growth to occur  
Nutrition rehabilitation will have been achieved when there is catch up growth to 1 centile below birth weight |
| SLT      | Eating and drinking skills are following appropriate stages for infant’s presentation.  
• Child is able to feed safely and independently and is growing appropriately.  
• Feeding is an enjoyable experience for child and carer.  
• All intervention advice and programmes are in place. Carers are skilled in carrying out recommended advice at which point infants should be discharged with support and re-referral options in place |

*Based on actual weight rather than expected weight
Appendix C:
An infant should have a SLT review if they
- Shows signs of distress during or after a feed
- Breathing sounds are noisy/ wet during or after a feed
- Coughing, gagging or choking episodes
- Losing fluid from the mouth or fluid/ food remaining in the mouth
- There are changes in breathing rate / saturation levels of breath holding during a feed
- Or if an infant changes colour during or after a feed
- Regression of oral feeding skills or oro-motor difficulties
- Difficulty in moving from enteral feeds to oral intake