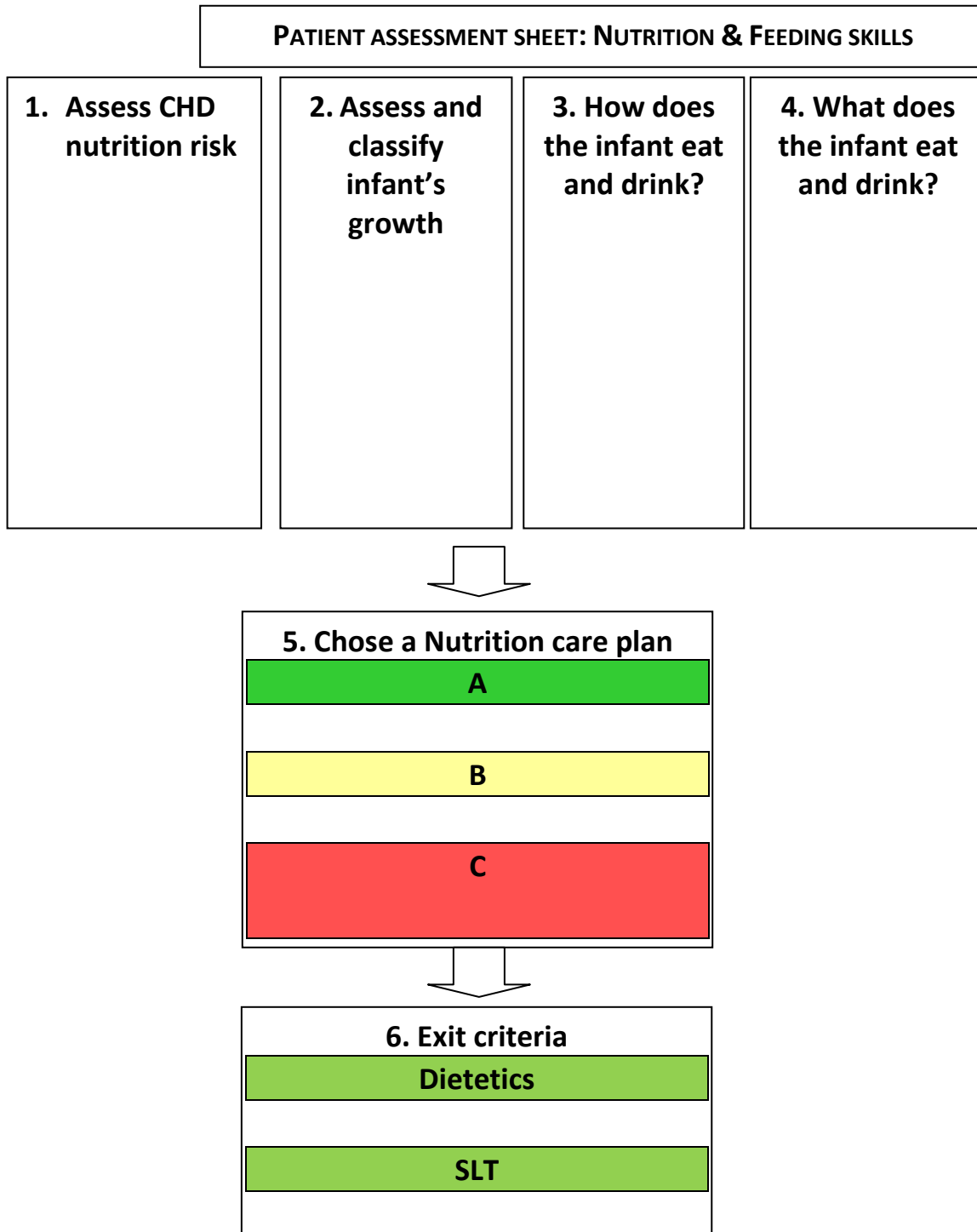


Supplementary File 3:

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.



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

Lower nutrition risk*	Higher nutrition risk*
<ul style="list-style-type: none"> • Patent ductus arteriosus – (if early surgery) • Atrial septal defect • Cor triatriatum • Total anomalous pulmonary venous drainage • Pulmonary stenosis • Transposition of great arteries • Coarctation of aorta <p>*This is not an exhaustive list and does not replace clinical judgement with respect to nutrition risk</p>	<ul style="list-style-type: none"> • Pulmonary atresia • Prostin dependent lesion • Tetralogy of Fallot • Atrial septal defect – (severe lesion) • Ventricular septal defect – (moderate to large) • Arterioventricular septal defect • Hypoplastic left heart syndrome • Truncus arteriosus • Aortopulmonary window • Patent ductus arteriosus (if large or delayed surgery) • Tricuspid atresia • Ebstein Anomaly • Double outlet right ventricle • Partial anomalous pulmonary venous drainage
<p>Notes:</p> <ul style="list-style-type: none"> • 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.

Lower nutritional risk	Higher nutritional risk
<ul style="list-style-type: none"> ▪ Gaining adequate amounts of weight e.g. approx. 10g/kg/day and length ≈ 2cm per month ▪ Weight/ length not more than 2 centiles below birth centile ▪ Following a growth curve which is not more than 2 centiles below birth centile 	<ul style="list-style-type: none"> ▪ Failure to gain adequate amounts of weight < 10g/kg /day and <2cm per month ▪ Sustained weight/ length drop of more 2 centiles or more from birth after 3 weeks of age ▪ Flattening growth curve or is dropping downwards e.g. losing weight

STEP 3 HOW DOES THE INFANT EAT OR DRINK?

Key message 3:

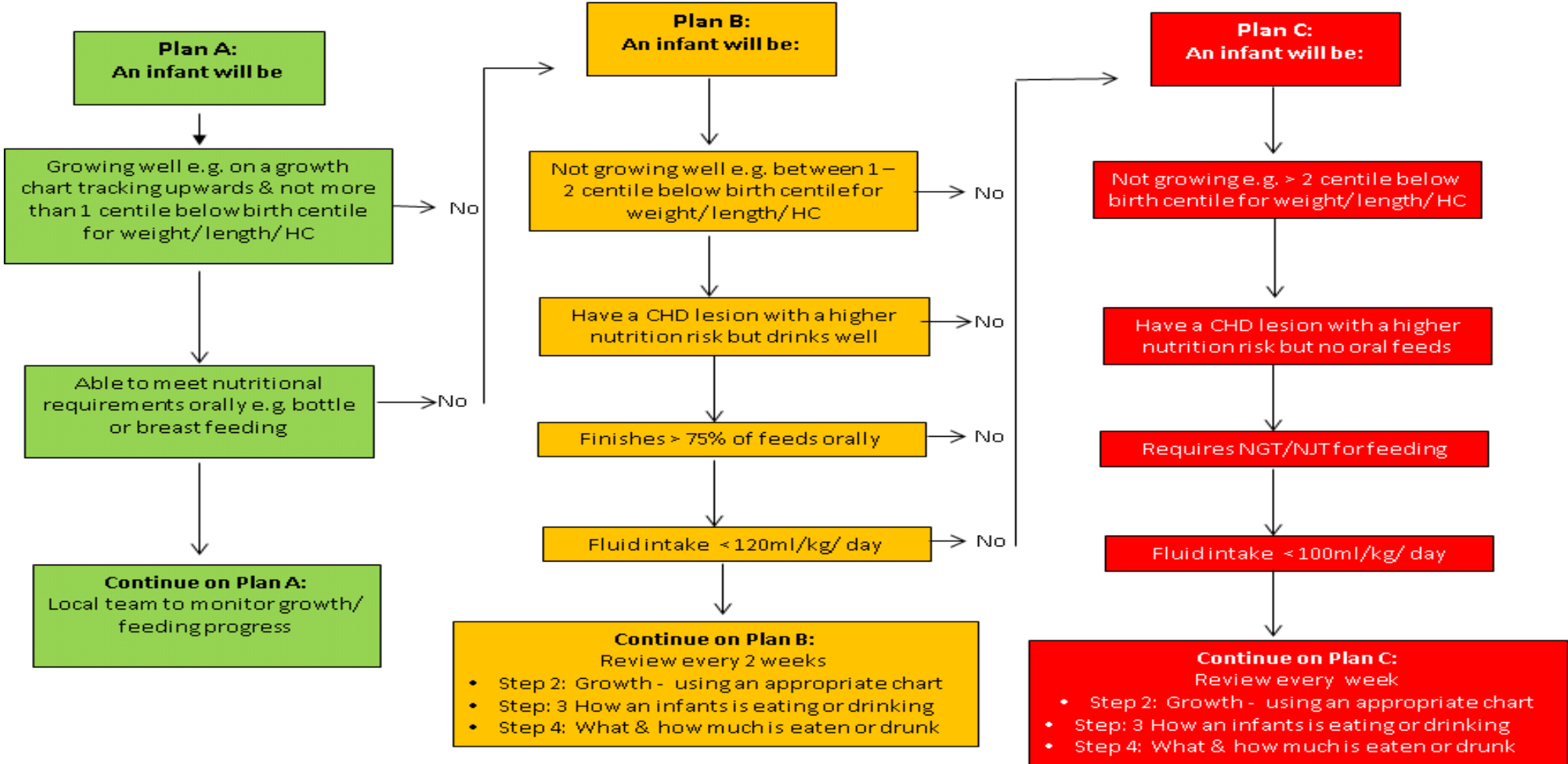
Prevent oral aversion by referring and involving a SLT early to assess feeding skills, particularly where there is a lack of progress or regression of feeding skills and associated clinical signs e.g. coughing, gagging or choking with feeds

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



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

Care Plan	Nutritional and feeding care plan
A	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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