

# Delphi consensus - Nutrition Guidelines in infants with CHD

---

Thank you for visiting our questionnaire page.

## Why are we doing this Delphi consensus?

Congenital heart disease (CHD) is one of the most common birth problems in infants, found in 9 out of every 1,000 babies born. We have shown poor growth in infants with CHD prior to surgery results in increased length of stay and post surgical morbidity.

The aim of these nutritional guidelines is to support the development of growth in infants (< 12 months age) with congenital heart disease (CHD) prior to surgery. The draft guidelines have been developed by the Paediatric Cardiology Dietetic/ SLT team at University Hospital Southampton NHS Foundation Trust (UHS), with support from the British Dietitian Association Paediatric Cardiac Interest Group. This questionnaire forms part of a Delphi consensus which we want to ask you as experts about.

## What happens next?

As experts taking part in this Delphi study you will be asked whether you agree or disagree with a set of statements regarding nutrition support in infants with CHD. There will also be an opportunity to provide comments as to whether you feel there is anything missing from each section. The study is anonymous to make sure everyone has an equal say. This Delphi study will be completed in 2 rounds using an on-line survey, with a final face to face meeting involving the British Dietitian Association Paediatric Cardiac Interest Group at UHS to validate the guidelines.

To be involved, simply complete this online questionnaire. It should take no longer than 5 - 10 minutes. It is entirely optional. If you do not wish to take part simply close the questionnaire. However we are really grateful for your opinions. There are no specific benefits to you from taking part but no risks either. All information you provide will be anonymous and cannot be withdrawn once you submit it. By completing the questionnaire you agree to participate in this process.

## Section 1. Step 1 - Assess & classify nutrition risk

The aim of these nutritional guidelines is to support the development of feeding skills and growth in infants (< 12 months age) with congenital heart disease (CHD) prior to surgery. There are five steps within the nutrition guidelines and these questions will go through each section in sequence.

**Using the scale from strongly disagree to strongly agree, please indicate the extent to which you agree or disagree with the following statements or questions.**

If you have any additional comments to add please use the comments box at the end of each section.

**Step 1 - the nutritional needs of infants with CHD will depend on the type of cardiac lesion**

## Step 1: Assess & classify nutrition risk

**All levels of health care professionals would be able to use these guidelines?**

Â

Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

**The nutritional needs of infants with CHD will depend on the type of cardiac lesions?**

Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

**It is important to develop someÂ nutrition guidelines for infants with CHD to improve growth before surgery?**

Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

**Infants with these cardiac lesions will have a lower nutrition risk**

	Stongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
Patent ductus arteriosus â€œ (if early surgery)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Atrial septal defect		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Cor triatriatum		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Total anomalous pulmonary venous drainage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Pulmonary stenosis		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

**Please write theÂ names, if any, of CHD lesions you feel should be included in the lower nutrition risk listÂ**



### Infants with these cardiac lesions will have a higher nutrition risk

	Stongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
Coarctation of aorta		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Pulmonary atresia		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Tetralogy of Fallot		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Atrial septal defect “ (severe lesion)		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Transposition of great arteries		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Ventricular septal defect “ (moderate to large)		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Arterioventricular septal defect		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Hypoplastic left heart syndrome		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Truncus arteriosus		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Aorto pulmonary window		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Patent ductus arteriosus (large/delayed surgery)		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Tricuspid atresia		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Ebstein Anomaly		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Double outlet right ventricle		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Partial anomalous pulmonary venous drainage		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

**Please write the names, if any, of CHD lesions you feel should be included in the higher nutrition risk list**

**Infants with more than 1 cardiac lesion AND a congenital or chromosomal abnormality will have a higher nutrition risk**

Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
T21/18/13	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
VACTRL/ CHARGE	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Gastrointestinal atresia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Di-George Syndrome	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Congenital chylothorax	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

**Please write the names, if any, of congenital abnormalities and CHD lesions you feel should be included in the higher nutrition risk list**





# An infant should have a SLT review if they

Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
Shows signs of distress during or after a feed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Breathing sounds are noisy/ wet during/after a feed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Coughing, gagging or choking episodes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Losing fluid from the mouth or fluid/ food remaining in the mouth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Changes in breathing/ saturation levels during a feed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
An infant changes colour during or after a feed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Regression of oral feeding skills or oro-motor difficulties	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Difficulty in moving from enteral feeds to oral intake	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Breath holding during a feed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

## Comments

## Section 4. Step 4 - What & how much is eaten/ drunk?

Restricted feed or food intake may impact on the infant's ability to maintain adequate nutritional status

### Infants with a lower nutrition risk will .....

	Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
Not vomit		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Drink 150ml/kg or above		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Keen to drink		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Finishes expected amount of infant feed		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Breastfeeds for expected duration		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

### Infants with higher nutrition risk will.....

	Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
Vomit with most feeds		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Be fluid restricted or drink		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Only drinks a portion of the feed offered		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Require a nasogastric tube		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

### Comments







# Comments

## Infants will no longer require intensive nutrition support when

	Strongly disagree	1	2	3	4	5	6	7	8	9	10	Strongly agree
They have achieved catch up growth to 1 centile below birth weight	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
They are 12 weeks post definitive surgery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

# Comments

Please check the button that best corresponds to you

### What is your gender?

- Male
- Female
- Prefer not to say

### About you

	<30 years	30 - 39 years	40 - 49 years	50 - 59 years	> 60 years
How old are you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### What is your professional background?

Specialist Paediatric Nurse	Registrar	SHO	Consultant Cardiology	Consultant other	SLT	Dietitian	OT	Physio	Health visitor	Community nurse	Other
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### How long have you been working with infants with CHD?

< 2 years	2 - 4 years	5 - 6 years	7 - 8 years	9 - 10 years	> 10 years
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### How would you describe your place of work?

Paediatric Surgical Cardiac centre	Regional Hospital	District General Hospital	Community
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please provide an email address to allow us to send your individual summary



**Thank you for taking time to complete this questionnaire.**