

# WC2 Univentricular Infants Home Monitoring

Scheme Name	WC3 Univentricular Infants Home Monitoring		
Eligible Providers	10 Children's Cardiac Surgical Units		
Duration	April 2016 to March 2017.		
Scheme Payment	CQUIN payment proportion [Locally Determined]		
(% of CQUIN-applicable contract	should achieve payment of c. £2,000* for each of		
value available for this scheme)	the expected number of infants under 6 months of		
	age with univentricular circulations suitable for		
	home monitoring prior to superior cavopulmonary		
	shunt operation.		
	Target Value: Add locally		
	CQUIN %: Add locally		
	*Any face to face outpatient payments that would be		
	triggered should be deducted.		

#### **Scheme Description**

Implementation of Home Monitoring Programmes for Children following Palliative Cardiac Surgery for patients with a primary diagnosis of: hypoplastic left heart syndrome, functionally univentricular heart or pulmonary atresia with intact ventricular septum. Collectively these conditions are referred to as univentricular hearts or univentricular circulations.

The scheme requires the 10 Children's Cardiac Surgical Units in England formally to establish a home monitoring programme for all infants with univentricular circulations discharged from hospital prior to their superior cavopulmonary shunt procedure (called the "interstage" period). The interstage period is a high-risk time for this group of infants. Mortality during this time is up to 20%, somatic growth is slow and parental anxiety high. The superior cavo-pulmonary shunt procedure stabilises the circulation but its successful completion requires infants to achieve reasonable growth. Evidence suggests the introduction of home monitoring programme reduces interstage mortality, improves rate of growth facilitating an earlier superior cavopulmonary shunt palliation.

Providers vary in the number of procedures undertaken. Individually, each centre would be expected to enter between 5 and 37 infants into a home monitoring programme annually. All infants entering this programme will be under 6 weeks of age.

The cost of the intervention is dependent on the number of infants on the programme per centre. Each family will require the loan of 1 set of infant scales and 1 portable pulse oximeter. The duration of the loan will vary between 6 – 12 weeks. The number of scales/oximeters required per unit will vary between 3 and 19 according to number of infants entering the programme and constitute the principle capital outlay required. The basic price of a pulse oximeter is £547 +VAT and of a set of infant scales is £664 + VAT. (Hence c.£1500 per child.) Suppliers will offer discount with multiple purchases in some cases.

Children's Cardiac Nurse Specialist (CCNS) time will be required to speak to families on a regular basis and review infants when they breach acceptable limits of weight gain or oxygen saturation. In some units this will be accomplished within current staffing levels, others may require extra CCNS time. An estimated 60 minutes per infant per week will be



required. (c.£100 for five weeks per child.) The lower activity units with an average of 5 children per year entering the programme, each requiring on average 8 weeks of home monitoring will therefore require an additional 40 hours per year of CCNS time. The higher activity units may require up to 296 hours of CCNS time per year.

The target payment should be based upon the expected number of patients requiring home monitoring through the year, with payment target based upon £2,000 per patient with deduction of any additional face to face outpatient payments that would be triggered as a consequence of implementation of this scheme.

## Measures & Payment Triggers

Numerator: number of infants under 6 months of age, with univentricular circulations prior to superior cavopulmonary shunt operation, who are following the home monitoring programme.

Denominator Total number of infants with univentricular circulations prior to superior cavopulmonary shunt operation suitable for home monitoring. (Expected to be 90% of all such infants.)

## Partial Achievement Rules

Following the initial capital outlay for equipment, allocation of CCNS time and agreement of extended protocols by individual Trusts, the home monitoring programmes should start immediately. An estimated run-in time of 2-3 months is reasonable, longer if recruitment of an additional CCNS is required.

Payment at the end of the year should be based on the % of patients with univentricular hearts discharged home during the interstage period on a home monitoring programme.

Allowing Q1 for introduction, payment should be based on performance in Q2-4 in total. 50% of whole-year CQUIN value if 80% infants enrolled 75% of whole-year CQUIN value if 90% infants enrolled 100% of whole-year CQUIN value if 100% infants enrolled

## In Year Payment Phasing & Profiling

For local agreement, bearing in mind the need for initial capital investment.

### **Rationale for inclusion**

The availability of a home monitoring programme will allow a greater number of infants to be discharged safely during the interstage period reducing the length of stay and the costs involved. The advantages in terms of greater somatic growth may reduce length of stay after superior cavopulmonary shunt and reduce morbidity. (Whilst current data is indicative of this it has not yet reached significance.)

Currently many centres offer home monitoring programmes for infants with hypoplastic left heart syndrome. This project aims to ensure that not only 100% of infants with hypoplastic left heart syndrome benefit from a formal home monitoring programme, but that this is extended to all infants with univentricular physiology in the period prior to superior cavopulmonary anastomosis.

This is considered to be a stretch for all units, even the units who have some level of home monitoring will need to expand their programme to fulfil the requirements of this CQUIN scheme.



Data Sources, Fr	equency a	nd res	ponsibility	for o	collection and reporting	

National Institute for Cardiovascular Outcomes Research (NICOR). The current level of utilization of home monitoring programmes can be assessed by asking each centre to declare a baseline. Data on the utilization of home monitoring will be verifiable by regional or local commissioners through regular dialogue. NICOR data is independently validated.

Valuerequiring home monitoring.Final indicator period/date (on which payment is based) & ValueUnits must report on utilisation relative to denominator (i.e. performance against the indicator).Final indicator reporting dateMonth 12 Contract Flex reporting date as per contract.CQUIN Exit RouteThis would be ensured by updating the paediatric congenital heart service specification to make the use of a home monitoring programme a requirement of commissioning. It will be further assured by introducing the utilisation of home monitoring into the quality dashboard	validated.	·
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### Supporting Guidance and References

Paediatric surgery for England, Wales and Northern Ireland is currently provided by ten centres all located in England. Validated national procedural data but not diagnosis-based data are available for all congenital cardiac surgical procedures undertaken in the UK. In 2013-14, 147 superior cavopulmonary shunts were undertaken in England in children under 1 year of age. Assuming an interstage mortality of between 5% and 15%, the expected number of infants entering the interstage period would be between 154 and 169 nationally. Of these 10 - 20% are likely to remain in hospital throughout the interstage period, up to 90% being suitable for discharge into a home monitoring programme.

Published data from Wisconsin (1) demonstrates a significant reduction in interstage mortality from 10-20% to 2% in patients with hypoplastic left heart syndrome following introduction of the home monitoring programme. Of all univentricular



circulations, hypoplastic left heart syndrome have the highest interstage mortality and therefore the improvement is most marked. Extension of the programme to other forms of univentricular heart has not shown a similar mortality benefit, possibly because the numbers are smaller; however benefits in terms of somatic growth are significant. Improved somatic growth is linked to earlier superior cavopulmonary shunt and improve transplant-free survival at one year (2, 3).

- 1. Rudd et al, J Thorac Cardiovasc Surg 2014;148:1540-7
- 2. Petit et al, J Thorac Cardiovasc Surg 2011;142:1358-66
- 3. Brown et al, JACC 2013;61:E452

The reduction in mortality whilst not immediately cost-saving is clearly cost-effective (if mortality falls by 13 percentage points, and the expected discounted QALYs for a surviving child were as little as five, the cost per QALY on the above figures would be only c. £2500, far short of the threshold of £15,000 per QALY).

Note, given the small numbers of babies involved and the fact that outcomes will not be measurable in terms of survival until 1 -3 years, it is not possible to quantify outcomes as part of the CQUIN scheme.