BI4 Improving Haemoglobinopathy Pathways through ODN Networks

Scheme Name	**BI4 Haemoglobinopathy Improving Pathways through Operational Delivery Networks**
Eligible Providers	For Providers identified as Lead Specialist or Specialist Haemoglobinopathy Centres. Until the Service Review for haemoglobinopathy is complete, this list is derived from historical agreements. The West Midlands Quality Review Service peer review reports also assess providers (this is external to NHS England processes) http://www.wmqrs.nhs.uk/review-programmes/view/haemoglobin-disorders-2014-16-reviews-adults-and-children The list of providers for whom the CQUIN should be considered as a priority is • University College London • Bart's Health • Birmingham Children's Hospital • Sandwell and West Birmingham • Central Manchester University Hospitals NHS Foundation Trust • Alder Hey Children's Hospital NHS Foundation Trust • South Tees Hospital NHS Foundation Trust • Newcastle upon Tyne NHS Foundation Trust • Leeds Teaching Hospitals NHS Trust • Sheffield Teaching Hospitals NHS Foundation Trust • Nottingham University Hospitals NHS Trust • University Hospitals of Leicester NHS Trust • University Hospitals Bristol NHS Foundation Trust • Oxford University Hospitals NHS Trust • *University Hospital Southampton NHS Foundation Trust (where link to London Trusts agreed)* • Barking Havering and Redbridge University Hospitals NHS Trust • Homerton University Hospital NHS Foundation Trust • Imperial College Healthcare NHS Trust • London North West Hospitals NHS Trust • North Middlesex University Hospital NHS Trust • King's College Hospital NHS Foundation Trust • Guy's and St Thomas' NHS Foundation Trust • Croydon Health Services NHS Trust • Lewisham and Greenwich NHS Foundation Trust • St George's University Hospital Trust
The eligibility criteria for this scheme are • NHS Trusts who have a contract with NHS England who are funded for activity	

associated with haemoglobinopathies as evidence by application of the Identification Rules

- Patients with sickle cell disease, thalassaemia or rare anaemias (adults and children) defined as specialised services. Other conditions not defined as specialised are excluded
- Providers must demonstrate they have the staff, skills and infrastructure to fulfil the specification / standards to be a Lead / Specialist Centre
- Providers must demonstrate via written evidence including terms of references and minutes that they have appropriately constituted MDTs making decisions about patient care. Quarters 1-3 update report required and quarter 4 annual report.
- Providers must evidence the governance for the ODN setting out the roles, responsibilities and pathways between the Specialist Centre, all other centres confirmed as caring for haemoglobinopathies in the ODN area, District General Hospitals (for acute / emergency / maternity pathways), primary care, voluntary organisations and links for screening and how these will be monitored, audited and updated. MDT arrangements and membership to be provided, particularly in relation to chelation therapy and complex care. Pathways covering emergency, elective, complex and routine follow up care to be supplied for children and adults. NHS England and local commissioners must be involved in approving ODN governance arrangements.
- Providers must demonstrate that they have sufficient data management capacity to ensure the complete and accurate submission of data to commissioners and to the National Haemoglobinopathy Registry http://www.nhr.nhs.uk/ for patients within their ODN area
- Providers must demonstrate they have the capacity and ability to offer annual reviews for all patients in their ODN area. The Protocol for the Lead / Specialist Centre annual review must be provided Plan is required demonstrating that by the end of year 3, 85% of all registered patients in the ODN area attend the Lead Specialist / Specialist Centre for annual review in accordance with the protocol.
- Provider must produce a baseline report setting out current arrangements including ODN area, partner organisations, patient numbers in care, % of patients attending for annual review over the last 3 years
- Providers are required to demonstrate improvements in patient experience and satisfaction as a result of implemented network arrangements compared to baseline. A plan to demonstrate this is to be produced and validated by the PPV team.
- Providers are required to demonstrate an improvement in patient outcomes. The definition and baseline for the measure to be proposed by each Lead / Specialist centre. The proposal to be validated with advice from the CRG chair and lead commissioner.

Duration	April 2016 to March 2019.
Scheme Payment	CQUIN payment proportion [Locally Determined] for year two and year three should achieve payment of £75,000 to £150,000 per provider per annum, according to scale of service provision and network responsibility: <500 registered patients evidence through 2016 Peer Review report supplemented by NHR report = £75K 501 – 2000 registered patients evidence through 2016 Peer Review report supplemented by NHR report = £100K 2001 – 5000 registered patients evidence through 2016 Peer Review report supplemented by NHR report = £125K

	> 5001 - registered patients evidence through 2016 Peer Review report supplemented by NHR report = £150K Target Value 2017/18: Add locally Target Value 2018/19: Add locally

Scheme Description

Problem to be addressed

Clinical consensus recommends haemoglobinopathy care be organised on a clearly defined network basis. This is set out in published standards produced by specialist societies for sickle cell disease and thalassaemia.

The prevalence of haemoglobinopathies across England varies widely, with the majority of patients concentrated around urban areas, as does the expertise to manage these conditions. The diseases mainly affect black and minority ethnic populations which often have poorer health outcomes. Despite this, there is not yet a comprehensive, approved network linking lead / specialist haemoglobinopathy centres with non specialist centres to provide a clear pathway for appropriate referral and care.

Change sought

This CQUIN incentivises removal of the remaining barriers to achieving an appropriate network of care by enabling lead / specialist centres to provide MDT led annual review of all patients and the associated communications, clinical support, staff training and data entry to demonstrate the clinical outcome benefits of such a model.

By augmenting the work on the Haemoglobinopathy CRG, the CQUIN incentivises approved providers to be responsible for appropriate governance relationships for national networking, ensuring efficient use of scarce specialist expertise / resource. This is especially important in view of a recent staff survey which suggests the availability of consultants will reduce further with many existing clinicians retiring in the next 5 years.

Specialist oversight improves appropriate and cost-effective access to appropriate treatment for haemoglobinopathy patients, including chelation therapy prescribing and monitoring, annual review and by developing ODNs and ensuring compliance with ODN guidance through MDT review of individual patients' notes.

Measures & Payment Triggers

Year One

Q1 Initial Network Meeting (10% Payment)

Specialist haemoglobinopathy centre, identified by commissioners as part of contract negotiation, to arrange an initial network meeting with local providers and commissioners to produce a proposal which defines the local area of oversight and that defines the patient group whose treatment is to be compliant with ODN protocols. This meeting must include patient/carer representation and should consider inclusion of local voluntary organisations. Two or more specialist haemoglobinopathy centres may hold this meeting together but achievement of milestone will be judged on individual submissions. The report following the visits to Area Teams (to be published) should provide a framework for local discussions.
Evidence: Meeting agenda and minutes. Proposal for commissioners defining geographical

area and local providers, and also the patient group whose treatment is to be compliant with ODN protocols. Terms of Reference for Network Group.

1. **<u>Q1/2 Agreement of Pathways and Protocols (30% Payment)</u>**
   Commissioners to sign-off proposal. Specialist haemoglobinopathy centre to arrange network meeting with local providers and commissioners to describe care pathways and agree areas where protocols will need to be developed. This meeting must include patient/carer representation and should consider inclusion of local voluntary organisations. This meeting may be held at the same time as the meeting described above and again may include two or more specialist haemoglobinopathy centres with the same rules applied regarding achievement.

Evidence: Meeting agenda and minutes. Including a description of care pathways and protocol areas which will need to be developed, a lead and a timescale for production.

2. **<u>Q3 Publication of care pathways and protocols & Arrangements for MDTs; Network meetings planned for 2017/18 (10% Payment))</u>**.

Evidence: Copies of all care pathways to be submitted and evidence provided that they are embedded into practice (e.g. screen shot of protocols on trust intranet; evidence of network in use recorded in patient notes; meeting arrangements for MDTs to review patients' notes). Copy of email confirming time of place of 2017/18 meetings.

3. **<u>Q4. Proportion of haemoglobinopathy patients with care reviewed by MDT to assure it accords to agreed ODN protocols. (50% payment)</u>**

Evidence: MDTs in place, patients reviewed, number of haemoglobinopathy patients.

Year two and three (subject to achievement of previous year triggers – otherwise subject to local adjustment):

Descriptions	**Second Year**	**Third Year**
Trigger 1:	Baseline report (annual, Q1)	Baseline report (annual Q1)
Trigger 2	Evidence of governance arrangements (quarterly reports)	Evidence of governance arrangements (quarterly reports)
Trigger 3	% of total registered patients in ODN attending for annual review at the Lead / Specialist Centre and plan to demonstrate performance to target of 85% by end of Yr 3 (quarterly reports)	% of total registered patients in ODN attending for annual review at the Lead / Specialist Centre and plan to demonstrate performance to target of 85% by end of Yr 3 (quarterly reports)
Trigger 4	Improvement in agreed patient satisfaction and outcome measure(s) (quarterly against baseline)	Improvement in agreed patient satisfaction and outcome measure(s) (quarterly against baseline)

Percentages of Target Payment per Payment Trigger

The following table sets out the proportion of the Target payment that is payable on achievement of each of the Payment Triggers.

Percentages of Target Payment per Trigger	**Second Year**	**Third Year**
Trigger 1	20%	10%
Trigger 2	30%	10%
Trigger 3	25%	40%
Trigger 4	25%	40%
TOTAL	100%	100%

Definitions

Lead and Specialist Centres – as per West Midlands Quality Review Service peer review programme definitions – see reports http://www.wmqrs.nhs.uk/review-programmes/view/haemoglobin-disorders-2014-16-reviews-adults-and-children

Annual review – To include Trans-Cranial Doppler screening for all eligible SCD patients and cardiac and liver MRI where indicated for patients with thalassaemia. Centre protocol to be provided

Registered patients – all patients in contact with haemoglobinopathy care services for their SCD or thalassaemia from 1st April 2015.

Partial achievement rules

Year One

Payments in Q1, Q2 and Q3 are paid if achieved on time in full.

Payment of Q4 milestone: under 50% achievement – no payment; above 90% achievement: Full payment; between 50 and 90% paid according to % achieved

Year Two

Trigger 1: *all-or-nothing*

Trigger 2: *all-or-nothing*

Trigger 3: *strictly-proportional* - under 50% achievement – no payment; above 90% achievement: Full payment; between 50 and 90% paid according to % achieved

Trigger 4: *strictly-proportional* - under 50% achievement – no payment; above 90% achievement: Full payment; between 50 and 90% paid according to % achieved

Year Three

Trigger 1: *all-or-nothing*
Trigger 2: *all-or-nothing*
Trigger 3: *strictly-proportional* - under 50% achievement – no payment; above 90% achievement: Full payment; between 50 and 90% paid according to % achieved
Trigger 4: *strictly-proportional* - under 50% achievement – no payment; above 90% achievement: Full payment; between 50 and 90% paid according to % achieved

In Year Payment Phasing & Profiling

In line with milestones

Rationale for inclusion

Clinical consensus states that specialised haemoglobinopathy care should be organised on a clearly defined network basis. This is set out in the following published standards:

http://sicklecellsociety.org/wp-content/uploads/2016/02/Standards-for-the-Clinical-Care-of-Adults-with-Sickle-Cell-Disease-in-the-UK.pdf

http://www.ukts.org/pdfs/awareness/standards2008.pdf

Providers should be part of an ODN for Haemoglobinopathy. Patients with haemoglobinopathy should have access to appropriate treatments in accord with ODN guidelines. This to be achieved through the development of protocols that will be implemented by MDT review of individual patients' notes.

This CQUIN is to support specialist haemoglobinopathy centres to work with commissioners and the wider haemoglobinopathy community to define and develop networks of care for patients with haemoglobin disorders.

The CQUIN focuses on developing partnership working across services which treat patients with haemoglobinopathies to define pathways and protocols; these may be commissioned through NHS England or through other commissioners

The establishment of these networks and the defining of local protocols for care has been slow across England; this CQUIN aims to prioritise and support the allocation of resource in order that these models of care may be progressed. There have been recent deaths reported which may have been prevented if protocols for access to specialist care had been in place and followed.

Data Sources, Frequency and responsibility for collection and reporting

Each specialist haemoglobinopathy service to submit routine data the National Haemoglobinopathy Registry
Determination following ODN set up and scope definition: To add measure of patients whose care should be in accordance with policy.

Reporting of Achievement against Triggers

Evidence of compliance with requirements of this CQUIN to be submitted directly to commissioners by trusts hosting a specialist service
Trigger 1: Baseline report – by Trust to commissioning team (annual, Q1)
Trigger 2: Evidence of governance arrangements – by Trust to commissioning team (quarterly reports)
Trigger 3: % of total registered patients in ODN attending for annual review at the Lead /

Specialist Centre and plan to demonstrate performance to target of 85% by end of Yr 3 – by Trust to commissioning team (quarterly reports)
Trigger 4: Improvement in agreed patient satisfaction and outcome measure(s) - by Trust to commissioning team (quarterly against baseline)

Information for Benchmarking and Evaluation

- WMQR peer review report for the centre / ODN providers
- National Haemoglobinopathy Registry data
- Trust reported data on activity
- Trust reported information on governance

Baseline period/ date & Value	
Final indicator period/date (on which payment is based) & Value	As above
Final indicator reporting date	Month 12 Contract Flex reporting date as per contract
CQUIN Exit Route *How will the change including any performance requirements be sustained once the CQUIN indicator has been retired?*	Three years will allow new procedures to be embedded and costs to flow into reference costs for inclusion in prices

Supporting Guidance and References

None