

Haemoglobinopathies CRG update

UK Forum meeting

May 2018



Content

- Hb Service review
- Policies in progress
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Aims of the service review

A review into specialised haemoglobinopathy services was initiated to address:

- Poor patient experience through variation in physical access to services and variation in specialist oversight and staff with knowledge of condition
- The issue of a small and declining workforce, lack of workforce planning and poor generalist engagement
- Variation in the quality of provider performance as indicated by dashboards and peer reviews
- Variation between providers in activity; in cost per patient; and in the rates of emergency admissions for individuals with SCD
- Lack of clarity as to what defines specialised care
- Financial constraints, meaning the new model must, as far as possible, be cost neutral



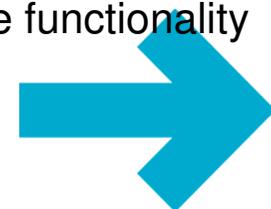
Other considerations

- Demand is increasing year on year
- Patients are unwilling to trade travel time/ distance for access for expertise. They require both so a different solution is required
- There are no consistent factors in determining quality. The strongest correlation is strength of network
- Using the National Haemoglobinopathy Register to identify all patients and support real time management is widely supported, assuming the issue of consent is addressed
- The horizon for new treatments is very high cost. Transformative treatments will need to be available to appropriately selected patients and the need for very specialist expertise will grow. This can only be achieved through national coordination



Our solution

- Commission and resource a number of network leads (Haemoglobinopathy Coordinating Centres (HCC)) with responsibility for leadership, education, protocol development. Will have to comply with a new service specification
- HCCs will work together to develop national protocols and standards
- Commissioners and HCCs identify a number of Specialist Haemoglobinopathy Teams (SHT) that meet a revised service specification and which are funded to deliver specialised care. For 2019/21 this is likely to be a block payment. We will need to be able to distinguish the elements of specialists care from routine clinical care.
- A year of care tariff for 2021/23 is proposed for clinical care.
- Institute a national MDT, which will accept referrals from SHTs with complex clinical problems and consider individuals who may benefit from new treatments, such as gene therapy, SCT etc
- Repurpose the specialised top-up (worth circa £5.8 million) to pay for the HCCs and SHT to be introduced in 2019/20
- Continue to develop the National Haemoglobinopathy Registry to improve functionality and to create a repository of patient information



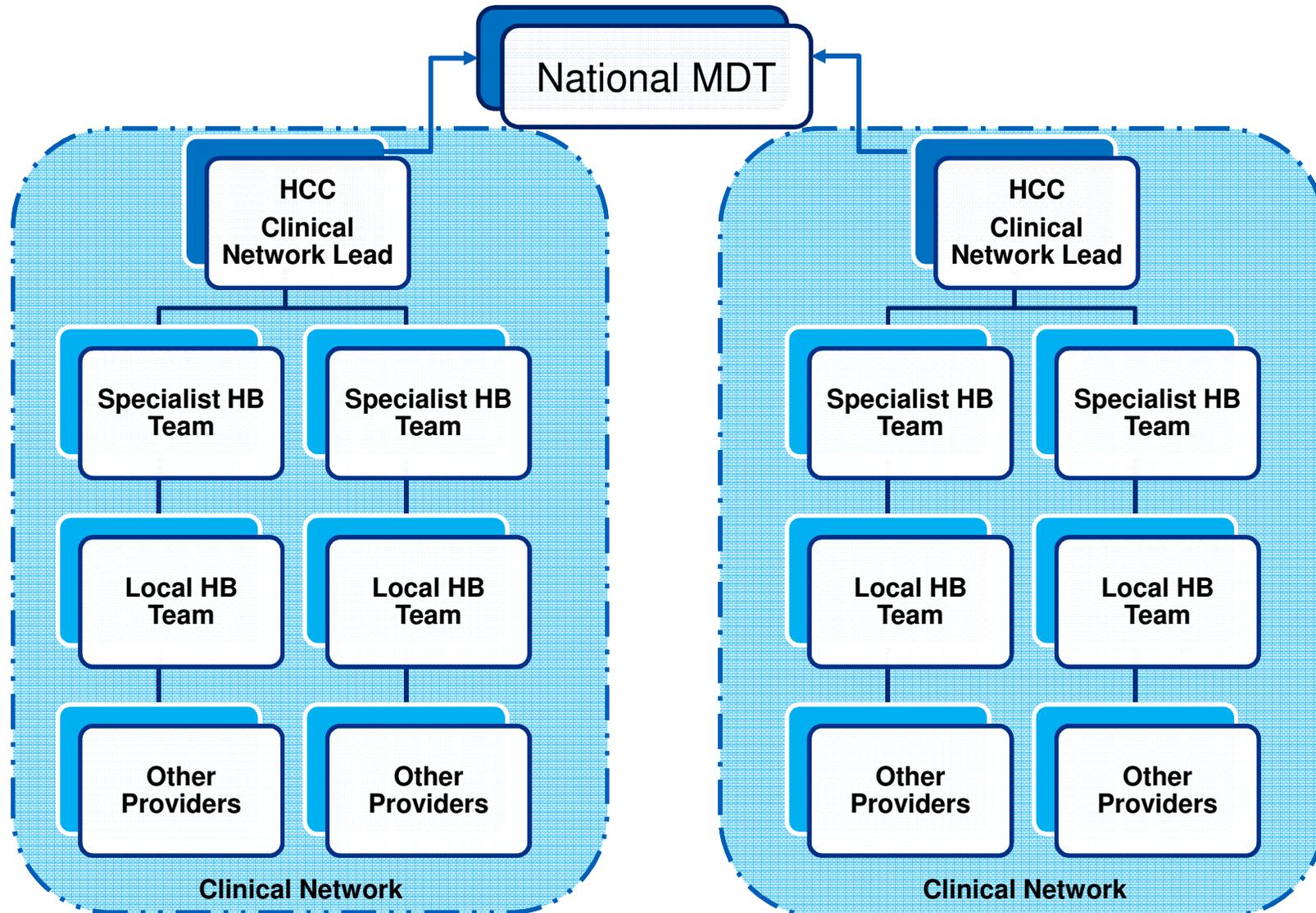
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we will need to be able to identify how SHT will be funded and any interim arrangements

Kate Ryan, 30/04/2018

The new model



The role of the HCC

Regional MDT

- Host Regional Specialist HB MDT which will discuss cases referred from the Specialist HB teams
- Contribute to the development of national guidance and clinical standards
- Support local MDTs
- Select patients for the National MDT



**Haemoglobinopathy
Coordinating Centre**

Service Improvement

- Conduct regular audits and benchmarking
- Ensure feedback from patients informs service improvement
- Ensure compliance with the Service Specification and commissioner requirements
- With commissioners address areas/providers requiring improvement or where there is lack of compliance;
- Monitor and ensure effectiveness of the clinical network and lead on its development

Clinical Functions

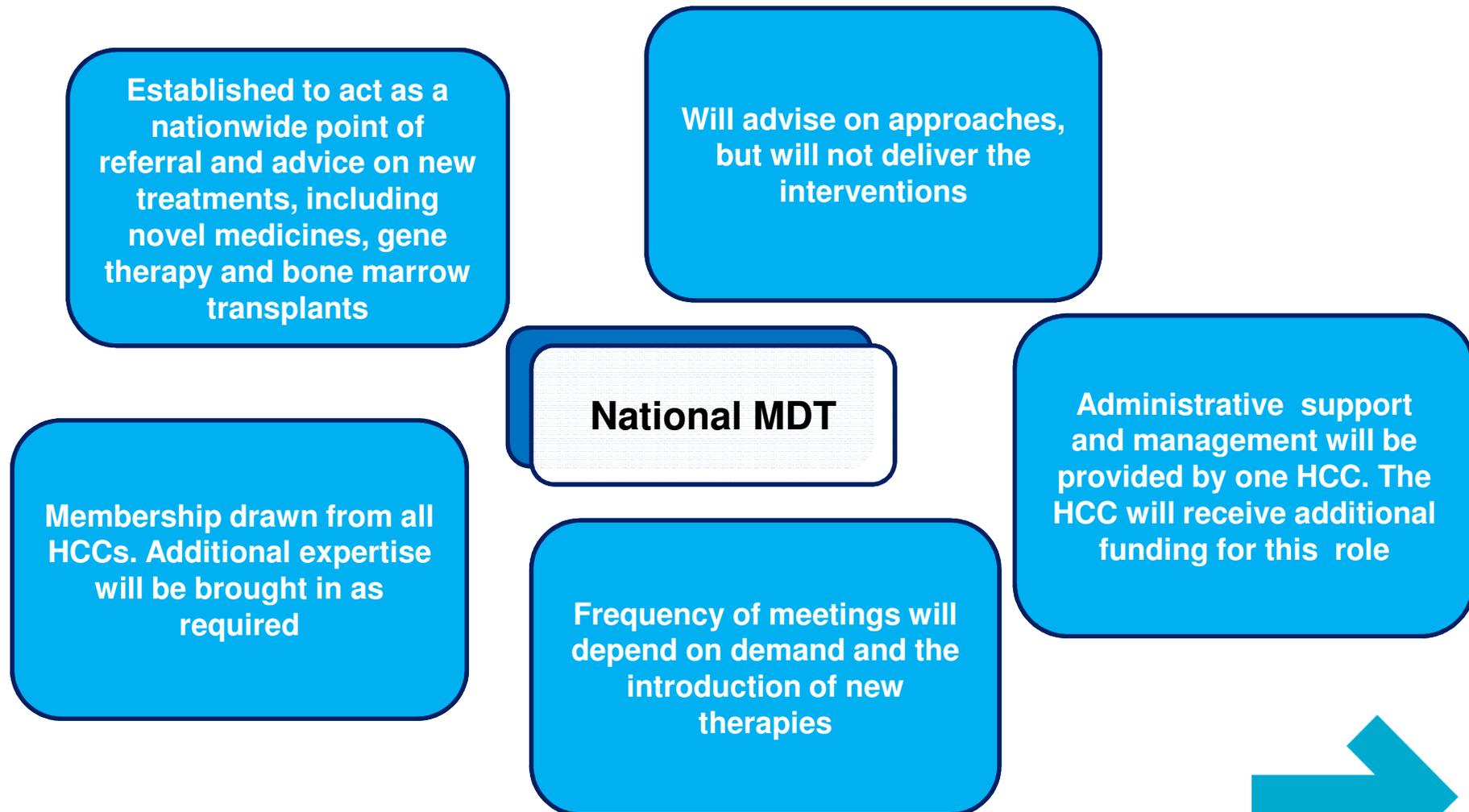
- Ensure effective running of the clinical pathways within the network;
- Ensure NHR data is submitted by organisations within the Network;
- Facilitate audit with Specialist Haemoglobinopathy Teams
- Ensure partner organisations conform to standards
- Oversee quality assurance
- Coordinate and take part in research studies

Education and Development

- Conduct regular educational needs analysis for providers in the network
- Develop and deliver clinical education for providers in the network with SHT
- Plan and conduct educational and training workshops with other providers for HB patients in the network
- Develop relevant patient education literature/leaflets

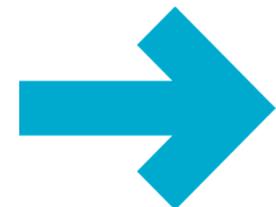


The role of the national MDT



What are the implications of the new approach?

- There will be a new service specification for HCCs, which will focus on administrative and leadership ability. The centres will be identified through a procurement process
- Trusts undertaking routine, non-complex care will no longer receive an additional top-up for the activity.
- Specialised activity delivered by Specialist Haemoglobinopathy Teams will be recognised and reimbursed
- Trusts that provide neither effective or efficient models of care in pain management will need to change
- We would expect that all patients in all areas will see a gradual improvement in the quality of the service they receive
- Patients will not see a significant change in the way their care is organised or delivered: the aim is to provide better specialist support and oversight of the care closer to home
- The majority of patients will continue to be treated where they are now
- Other components of the service will be implemented over time



Next steps

- Public consultation on the future state, service specification and contracting approach to start in June
- Procurement of the HCCs in September
- Implementation of the future state for April 2019 contracting round
- Continue to develop the NHR
- Aim to develop a year of care tariff to support good practice for implementation in 2021/2023 contracting round. We will explore an interim block payment arrangement for implementation in 2019/2021



Other work streams

Policies in progress

- RIC sibling SCT for Adult SCD
 - *Policy at Clinical Panel today!*
- Eculizumab and Rituximab for delayed HTR/hyperhaemolysis in SCD
 - *Approved by clinical panel for further development of a clinical policy*



Research priorities agreed with NHSE

- SCT in Adults with SCD
- Hydroxycarbamide for asymptomatic children with SCD cerebrovascular disease (silent infarcts)
 - *Research proposals to be submitted to NIHR. Does not guarantee funding by NHR however*

Tariff work in progress

- Improved tariff for automated RCE
- Year of care tariff for SCD and Thalassaemia/RIA

