

Haemoglobinopathies Service Review

Update: the Case for Change

Kate Ryan, CRG Chair
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Root causes leading to the review

- **Poor patient experience** – variation in physical access to services, especially transfusion/ apheresis
- **Poor patient experience** – variation in specialist oversight and staff with knowledge of condition
- **Staffing** – insufficient workforce to run the current model; poor generalist engagement; scope for better skill mixing
- **Provider performance (quality)** – variable as per dashboards and peer reviews
- **Provider performance (activity/cost)** – significant variation in cost per patient and in the rates of emergency admissions for individuals with SCD
- **Provider configuration** – a lack of clarity and understanding as to what defines specialised care

What we found

1/2

- Patients are unwilling to trade travel time/ distance for access for expertise. They require both so a different solution is required
- The vast majority of people who access haemoglobinopathy services do so via a hospital trust close to their local CCG
- Provider consolidation would negatively impact access
- The workforce issues mean that only a network model will work
- There are no consistent factors in determining quality. The strongest correlation is strength of network
- Lead provider model is not supported by clinicians, providers or commissioners
- National registry to identify all patients and support real time management is supported but there will be consent issues to overcome. There is also support for the registry to become available to patients
- Workforce planning is very difficult: it is not prioritised by anyone

What we found

2/2

- Personalised care planning and empowerment, whilst supported by patients and clinicians alike, will need dedicated work. A possible proxy for engagement is reported DNA rates for outpatient activity, which is at circa 30-40% . Patient led insight into causes and alternatives will be required
- The horizon for new treatments is very high cost. Transformative treatments will need to be focused on carefully selected patients and the need for very specialist expertise will grow. This can only be achieved through national coordination
- The financial impact is likely to be roughly cost neutral. This assumes savings, which can only be realised with investment in the components of the new service model. Investment is assumed to come from savings from a reduction in admissions, particularly emergency admissions, and a redistribution of the specialised top-up

Future state

1/2

The CRG has concluded that to design a future state which really addresses the root causes of the current levels of variation in quality and access, a new model is required, which recognises that:

- Patients, particularly those with SCD, need ***very local access to urgent care*** whilst demonstrating an understanding of haemoglobinopathy care
- Patients with ongoing transfusion requirements also need ***access to responsive local services*** to reduce or avoid time off school or work
- These conditions can have particular complications throughout a patient's life. This means ***specialist oversight and coordination*** is critical in improving outcomes
- As with other long term conditions, there is a significant role for informed empowered expert patients and ***making better use of technology in an appropriate way***

Future state

2/2

- Providers, patients and commissioners all need clarity about what constitutes specialised and specialist care. All need to have a shared understanding as to ***which services are required for which interventions***
- There is the real and potentially intractable issue of sufficient specialist staff. This requires a way of ***organising care which allows everyone to access expert advice***
- There is a clear need to allow ***locally appropriate service delivery***
- However, there is also significant scope to ***develop and adopt national protocols*** and service models such as those dealing with chronic pain management to reduce the inappropriate use of emergency admissions

Achieving the future state 1/2

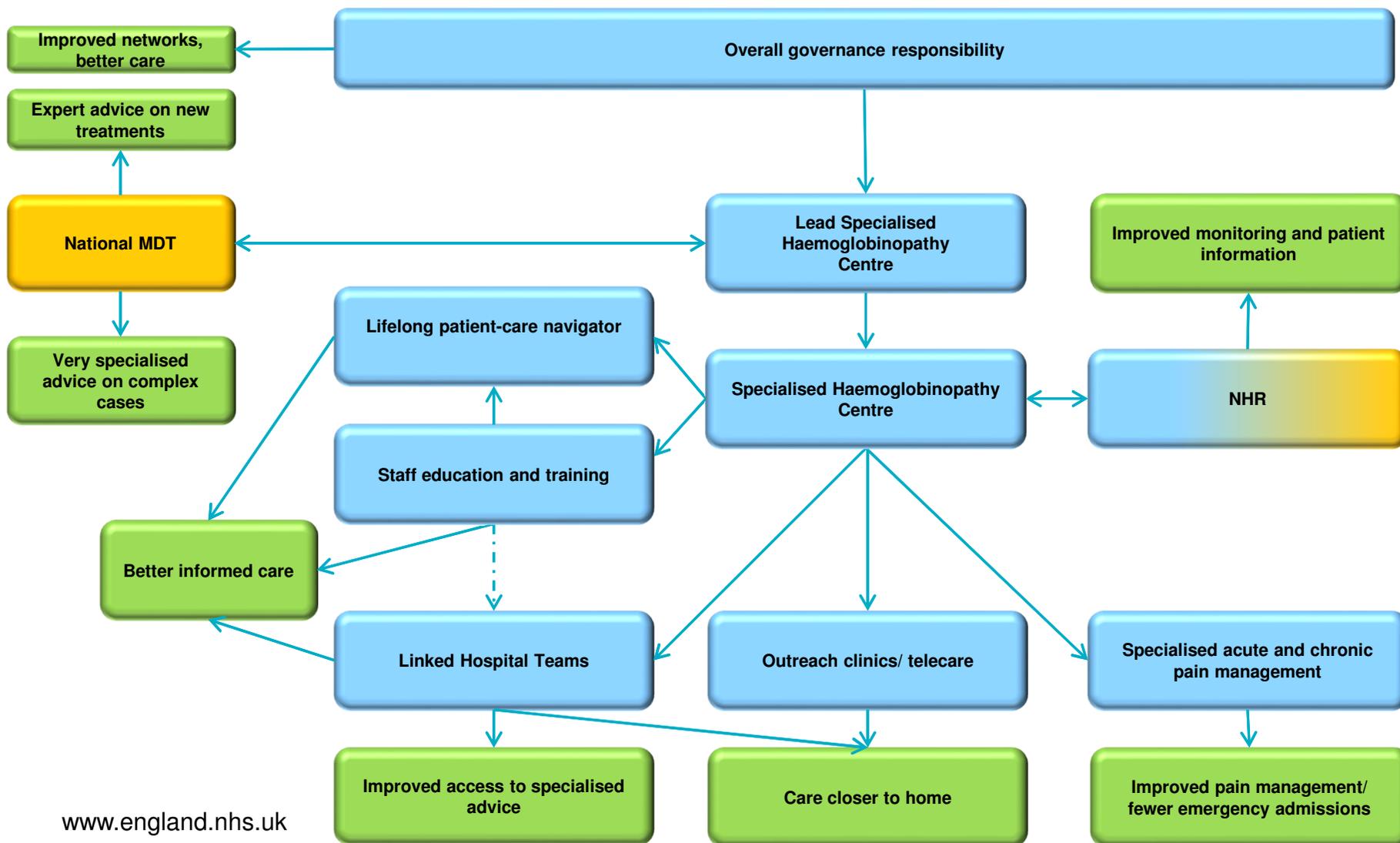
- **Identifying a number of specialist centres.** The approach has yet to be confirmed, but will include provider and clinical engagement
- **Mandating that specialist centres and local services are linked formally.** Primary and community care are key elements of the team and will provide holistic care to patients under the guidance of specialised centres
- **Using contracting levers** to ensure the use of national protocols, such as the NHR and service models
- **Establishing a National MDT.** Specialist centres will be required to constitute a national MDT which will be available to provide 24/7 advice on complex cases and very specialised treatments
- **Redefining and contracting for the National Haemoglobinopathy Register.** The NHR is underutilised, yet represents a significant resource for both patients and clinicians.
- **Developing clinical policies** to positively ensure equitable access to treatments, such as hydroxycarbamide and apheresis

Achieving the future state 2/2

Some *pricing solutions* are required in order to:

- Appropriately *distinguish between specialist care using specialist staff and skills and more routine care* and ensuring that the specialist top up is only applied in recognition of truly specialist care
- *Recognise the additionality of the care provided by lead specialist centres* including its contribution to running the national MDT. This could be in the form of the top-up
- *Incentivise the adoption of best practice*. This could be a year of care approach or best practice tariffs for care components. This needs further development

Future model



Next steps

