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National Haemoglobinopathy Panel
Terms of Reference

Introduction

The National Haemoglobinopathy Panel (NHP) was commissioned in January 2020, to provide strategic direction and leadership of Haemoglobinopathy care and support the Haemoglobinopathy Co-ordinating centres (HCCs) from an operational and clinical perspective.

The National Haemoglobinopathy Panel multidisciplinary team (MDT) meeting, with membership drawn from the HCCs, will provide timely advice on complex cases that need access to wider range of expertise or opinion that may not be available at the SHT/HCC, or will support their decisions. It is not intended to replace local pathways for clinical advice which are detailed in the service specifications for the SHT and HCC. The clinical responsibility of a patient remains with the treating clinician.

1. Roles and Responsibilities

The primary role of the NHP is to provide expert and evidence-based advice on the management of adults and children with sickle cell disease, thalassaemia and rare inherited anaemias, as and when requested by the clinicians caring for these patients. All HCCs will be required to collaborate with the National Haemoglobinopathy Panel (NHP).

The NHP will work alongside the Specialised Haemoglobinopathies Clinical Reference Group (CRG), the HCCs, the Blood and Marrow Transplantation/Cellular Therapy (BMTCT) subgroup, the SHTs and other key bodies in haemoglobinopathies care in order to:

1. Drive the delivery of a nationally consistent approach to care envisaged by the CRG and approved by commissioners
2. Coordinate the actions taken at SHT and HCC levels to deliver access to specialist oversight and to reduce unwarranted variation
3. Provide SHTs and HCCs access to national expert clinical opinion with regard to the treatment of complex patients
4. Support the introduction of commissioned innovative therapies by acting as a national panel to consider individual patients most able to benefit and to enable patients to have access to these therapies, irrespective of where they live.

2. Term

The contract for coordination of the National Haemoglobinopathy Panel will be reviewed every 3 years. This Terms of Reference is effective from 1st January 2024 and continues until the 31st December 2026, or will be ongoing until terminated by agreement between the parties.

3. Membership / Panels

a) Core MDT Panel Membership

- Clinical Lead representation from each HCC

- Adult and Paediatric Sickle Cell Disease Leads
- Adult and Paediatric Thalassaemia Leads
- Rare Inherited Anaemia Lead
- Adult and Paediatric Blood and Marrow/Cellular Therapy (BMTCT) Leads
- Further specialists to be included:
  - Rare Anaemias
  - Thalassaemia
  - Sickle cell disease
  - Bone marrow Transplant/ Cellular Therapies
  - Psychologist
  - Clinical Nurse Specialist for Sickle cell disease/ Thalassaemia
  - Pharmacist
  - Invited specialists for individual cases as clinically indicated to include; Neurology, Cardiology, Nephrology, Ophthalmology, Orthopaedics, Endocrine and Metabolic, neuropsychology, obstetrics and gynaecology, ethical consideration etc.

b) Administrative Non-MDT steering committee/Business Operations & Governance Group

This aspect of The National Haemoglobinopathy Panel will comprise:

- NHP Chair
- Deputy NHP Chair
- NHP Operational Support Officer
- All permanent members of the MDT representing all HCCs + KHP Manager
- Patient societies – UK Thalassaemia and Sickle cell Society
- Clinical Reference Group (CRG) chair
- BMTCT Leads
- National Haemoglobinopathy Registry (NHR)
- TCD QA lead

Function:

Twice yearly business meetings to:

- Oversee and develop the NHP's activities
- Review the NHP's performance data
- Establishment of TCD QA systems
- Review outcomes of peer review where appropriate to the role of HCCs/SHTs and to the role of NHP
- Review HCC and related programme progress and learn from network partners
- The NHP may provide additional educational meetings to compliment other activities by HCC, UK Forum on Haemoglobin disorders and other relevant bodies.
- The NHP will review mortality/morbidity outcomes from MDT and national mortality/morbidity data to inform the CRG of any changes required in national policy.
- The NHP will maintain a list of currently open clinical trials and NICE approval process for relevant new therapies.

c) Email MDT Group

- Members of the Core panel and any additional required specialist and clinician will be included in the email MDTs.
- A feedback report will utilise an approved template to be sent to:
- Primary referrer i.e. clinician

- Report to patients through their clinician.
- Relevant SHT/ HCC administrator for learning purposes

4. MDT Function

- Referrals will be accepted directly via the SHT or HCC MDT arrangements or directly from clinicians, depending on what is most appropriate for the patient and the local network.
- The frequency of meetings will depend on the clinical needs of complex patients. The NHP is expected to use available technologies to improve the efficiency of meetings.
- The clinical responsibility of a patient remains with the treating clinician.

Two tiered system

Video MDT

- We will schedule the videoconference MDTs on a monthly basis, with up to 10 cases per agenda. Meetings will be scheduled quarterly in advance, at the latest, to ensure members are able to attend and the dates published on the NHP website
- Clinicians will be invited to submit cases for review to the coordinator by nhs.net email using the proforma, accepted until 10 days prior to the meeting. The coordinator will remind the SHTs and HCCs of the upcoming meeting by email
- The NHP chair will review the referred cases to ensure their eligibility. If a case does not meet the referral criteria then the chair will signpost to alternative support, in most instances this would be to the relevant HCC MDT or NHP's email-MDT
- Once the cases have been reviewed, the coordinator will publish the agenda for the NHP 5 days prior to the event, providing the participating core and relevant co-opted members (invited as required) sufficient time to review the cases. The cases for review will be accessible in a nominated folder on the NHP SharePoint site. The referring clinician will be invited to present their case at the MDT
- The NHP's recommendations will be recorded by the coordinator and stored on the SharePoint site
- Additional meetings will be scheduled as required. If warranted by the number and types of referrals, paediatric, transition or condition-specific meetings may be scheduled, at which there would be a tailored panel

Email MDT

- This supports urgent cases not to be delayed for the monthly MDT
- Clinicians will be invited to submit cases by email using the proforma
- The NHP chair (Deputy Chair in absence of Chair) will triage referrals on a weekly basis, signposting ineligible cases to the NHP's videoconference MDT or relevant HCC MDT
- Members will have 2 days to respond, after which the chair will compile the panel's recommendations which will then be sent to the referring clinician.

Recommendations will be logged on the NHP SharePoint site.

5. Nature of Video-MDT Meetings

All meetings will be chaired by the Chair of the NHP or their deputy.

A meeting quorum will be the Chair/Deputy and five additional members.

Decisions will be made by consensus (i.e. members are satisfied with the decision even though it may not be their first choice). If not possible, the NHP Chair will make the final decision.

The meeting agendas and minutes will be provided by the NHP co-ordinator/manager.

Referral Criteria			
Sickle Cell Disease	Thalassaemia	Rare Anaemia	Comments
All Referrals for stem cell transplantation, including sibling, MUD and haploidentical matched donor	All referrals for stem cell transplantation including sibling matched, MUD and haplo matched donor	All Referrals for stem cell transplantation, including sibling, MUD and haploidentical matched donor	Are Rare Anaemia better suited elsewhere rather than with haemoglobinopathies? Is it because of specialist commissioning?
All referrals for new therapies, such as Gene Therapy	All referrals for new therapies, such as Gene Therapy	All referrals for new therapies, such as Gene Therapy	All referrals for new therapies, such as Gene Therapy
New therapies bearing in mind NICE guidance and patient benefits	New therapies bearing in mind NICE guidance and patient benefits	New therapies bearing in mind NICE guidance and patient benefits	
Complex cases that require expert opinion outside HCC/SHT	Complex cases that require expert opinion outside HCC/SHT	Complex cases that require expert opinion outside HCC/SHT	
Uncontrolled/excess accumulation of liver iron concentration (LIC)	Cardiac iron e.g. reduced FS<20%, cardiac iron <		
Patients being considered for (or having received emergency treatment) with Eculizumab for the treatment or prevention of Delayed Haemolytic Transfusion Reaction (DHTR)	Patients being considered for (or having received emergency treatment) with Eculizumab for the treatment or prevention of Delayed Haemolytic Transfusion Reaction (DHTR)	High Cost therapies	

More details on the referral criteria

Sickle cell disease

1. Referral reviews and discussions will draw on current guidance to avoid inappropriate referrals.
2. It has been agreed that BMT and Gene Therapy referrals must go through the NHP MDT approval process. However, the NHP will work closely with the BMTCT subgroup in ensuring well-informed decision-making.
3. Minimum policy requirements for gene therapy will be incorporated in decision-making according to the treatment protocol inclusion and exclusion criteria
4. Clinicians need to undertake full patient work-up before panel referral
5. To consider excluding cases within licensed criteria
6. Equity of access for gene therapy and stem cells should be considered and discussed by the HCCs.
7. If NHSE is required to pay for the case, it will need to come to the panel.
8. NICE recommendations will play a role in guidance on new drug approvals

Thalassaemia:

1. Any patient in whom splenectomy is being considered should be brought to the panel
2. BMT, gene therapy, rituximab/eculizumab for haemolysis will be discussed by the panel.

3. NTDT patients who may need regular transfusion could also be discussed.
5. Patients with cardiac iron do not routinely need to come to the panel, but should be brought if complex. There needs to be flexibility about which iron loaded patients would need to be discussed.

Suggested referral criteria to NHP for Rare Inherited Anaemia:
This applies to children and adults with rare inherited anaemias if they require intermittent or long term transfusion and/or chelation therapy, or if there are other questions about their management, including whether they should undergo splenectomy or be referred for haematopoietic stem cell transplantation.

These inherited red cell abnormalities include:

1. Congenital dyserythropoietic anaemia
2. Unstable haemoglobins
3. Red cell membrane abnormalities with a severe/complex clinical phenotype including hereditary pyropoikilocytosis and severe forms of hereditary spherocytosis defined by a requirement for intermittent or regular transfusion
4. Disorders of red cell hydration – including stomatocytoses
5. Red cell enzymopathies – including pyruvate kinase deficiency, G6PD deficiency causing chronic haemolysis necessitating transfusion therapy
6. Disorders of haem synthesis - including congenital sideroblastic anaemia
7. Diamond Blackfan Anaemia
8. Other anaemia due to haemolysis or defective erythropoiesis requiring regular transfusion that are likely to have a heritable basis.

Consensus

1. HSCT referrals will all be brought to the panel
2. Non sibling transplants need to go through the panel.
3. Gene therapy would come to panel, with input from the transplant/cellular therapy group, pending NICE recommendations
4. Any new drugs licenced within NICE recommendation would not have to come to the panel (but should be referred if there is a lack of clarity or controversy about eligibility
5. Any complex case could come for discussion (preferably via HCC)
6. Thalassaemia needing splenectomy should be tabled for the panel
7. Patients needing rituximab/eculizumab for treatment of DHTR should be tabled for the panel including for retrospective approval

6. MDT Process

Frequency

The video conference call will be held monthly to discuss cases referred to the national haemoglobinopathy panel. To ensure that the experts have adequate time to review the cases, summarised referral will be sent out by secure email (preferably NHS.Net or doctors.org) to the NHP secure email.

The meeting will be for two hours and the day of the week will be pre-determined by the full MDT on a 6-12 monthly basis, in order to ensure that specialists are invited well in advance, to avoid clashes with other clinical responsibilities.

Specialist composition

The multi-disciplinary team (MDT) will consists of professionals representing all the Haemoglobinopathy coordinating centres (HCC) across the country, representing all professional groups involved in the care of patients with disorders described within the specialist haemoglobinopathies services – sickle cell disease, thalassaemia and rare inherited anaemias. It is anticipated that the breadth of specialists, as much as possible, will reflect the pattern of referrals and

the clinical issues at hand. Only clinical professionals will participate in the multidisciplinary meeting (MDT), patient representatives will not be invited at these meetings. In order to protect the clients' confidentiality, patients will be anonymised and the discussion will take place using a secure communication medium either encrypting zoom conference or Microsoft Teams. The medium for video conference will be reviewed from time to time to ensure adequate functionality and patients'/clients' confidentiality.

Decision-making process

All cases referred to the NHP will be assessed by the NHP chair or the Deputy NHP chair and follow the necessary action either by referral to:

1. Email panel and the relevant specialist(s) on the database for emergency response. The panel members will receive the referral and the response sent to the NHP chair within 7 days of the specialist receiving the referral. The final report will be approved by the NHP chair or his/ her deputy.
2. Video panel for the MDT to discuss during the monthly call

Referrals for the video MDT will also be reviewed by other experts (such as NHSBT and BMTCT) ahead of the wider sharing of these documents and subsequent meeting, in order to review and prepare potential actions needed for input and planning on the day.

The intention is to achieve the outcome of decisions by consensus. However, in the event that this remains unresolved, the NHP Chair will advise the referring consultant of this and where there is a substantial cost implication this may need to be referred to a separate list of experts on the database of experts for adjudication.

An outcome form will be filled and sent to the referrer, using a template response, which may be reviewed from time to time. The NHP shall endorse these reports.

Full minutes of the meeting will also be shared with MDT attendees.

7. Amendment, Modification or Variation

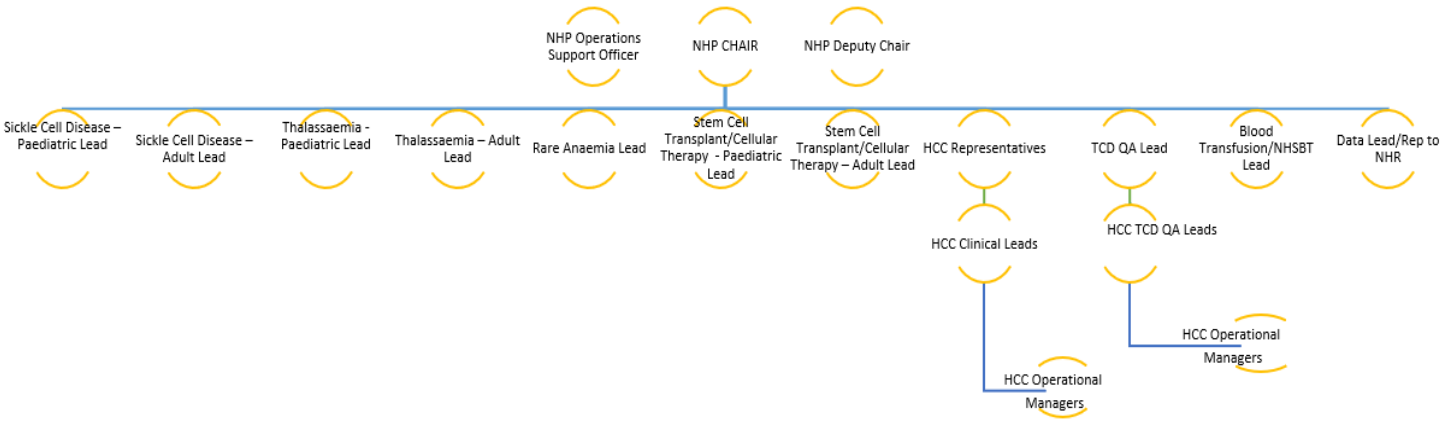
This Terms of Reference may be amended, varied or modified in writing after consultation and agreement by the National Haemoglobinopathy Panel Group members.

8. Declaration of interests

All members will make a formal declaration of interests which will be publicly available on request. This will include details of work with pharmaceutical companies, advisory boards, support to attend meetings, grants, involvement in clinical trials, and research studies. Members should not participate in decisions where there is a potential conflict of interest.

9. NHP Structure and Key Relationships

NHP Structure and Key Relationships



NHP WIDER NETWORK AT A GLANCE