

National Haemoglobinopathy Panel Terms of Reference

Introduction

The National Haemoglobinopathy Panel (NHP) will 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 meeting (MDT) 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 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, 2020 and continues until the 31st December, 2023 will be ongoing until terminated by agreement between the parties.

3. Membership / Panels

- a) Administrative Non-MDT steering committee of The National Haemoglobinopathy Panel will comprise:
- NHP Chair
 - Deputy NHP Chair
 - All permanent members of the MDT representing all HCC + KHP Manager

- Patient societies – UK Thalassaemia and Sickle cell Society
- Clinical Reference Group (CRG) chair
- National Haemoglobinopathy Registry (NHR)
- TCD QA lead

Function:

- Meeting four times in the first year and twice yearly thereafter in order 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 role of HCCs/SHTs and to role of NHP
- 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.

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 systems

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 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 14 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 7 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

- Cases for review by the email-MDT and report back with 7 days. this
- 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
- Confidential Secure App will be used to deposit MDT reports and recommendation.
- **Members will have 7 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 Email panel

A pool of experts will be invited to join the email panel in order to be contacted for advice regularly.

MDT Panel Membership including core

- NHP Chair and Deputy
- HCC representatives
- **Specialists to include**
 - 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.

A panel of experts will be maintained who may be co-opted onto meetings:

- Stem Cell Transplant
- Cardiology
- Pain Management
- Renal
- Obstetrics
- Neurology
- Urology
- Respiratory

- Endocrinology
- Fertility
- Orthopaedic
- Pharmacy
- Psychology
- Liver
- ENT Surgeons
- Anaesthetist
- Blood transfusion specialist
- Vascular surgery
- Orthopaedic and reconstructive surgery
- Etc- as required

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. 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 which involves:

Referral Criteria

Referral Criteria			
Sickle cell disease	Thalassaemia	Rare Anaemias	Comments
All referrals for stem cell transplantation including sibling matched donor, MUD and HAPLO-matched.	All referrals for stem cell transplantation including sibling matched donor, MUD and HAPLO-matched.	All referrals for stem cell transplantation including sibling matched donor, MUD and HAPLO-matched.	Is Rare Anaemias better suited elsewhere rather than with haemoglobinopathies, is it because of specialist commissioning?
All referral for new therapies such as Gene Therapy,	All referral for new therapies such as Gene Therapy,	All referral for new therapies such as Gene Therapy,	What about private patients receiving treatment in the UK, they may be considered but only advisory
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	Cardiac Iron e.g. reduced FS <20%, cardiac iron <		
Patients being considered (or having received emergency treatment) with rituximab or eculizumab for the treatment or prevention of delayed haemolytic transfusion reaction	Patients being considered (or having received emergency treatment) with rituximab or eculizumab for the treatment or prevention of delayed haemolytic transfusion reaction	High cost therapies	

More details on the referral criteria

Sickle cell disease

1. Raise Awareness on current guidance to avoid inappropriate referrals.
2. It was agreed that BMT and Gene Therapy must go through the NHP MDT.
3. Clarification is being sought on the minimum policy requirements for gene therapy
4. Emphasise the 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 and this should be discussed by the HCC's.
7. If NHSE is required to pay for the case then it will need to come to the panel.
8. New drugs, the role of NICE recommendation to be the guide

Thalassaemia:

1. Any patient in whom splenectomy is being considered should be brought to the panel
2. BMT, gene therapy, rituximab/eculizumab for haemolysis.
3. NTDT patients who may need regular transfusion could also be discussed.
4. Luspatercept was highlighted as upcoming therapy
5. Patients with cardiac iron did 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 anaemia

This applies to children and adults with 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 start regular transfusions, 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 would all be brought to panel
2. Non sibling transplants need to go through the panel.
3. Gene therapy would come to panel, also depends on NICE recommendations
4. For new drugs if they were within license and NICE recommendation they did not have to come to panel (but should be referred if lack of clarity or controversy about eligibility)
5. Any complex case could come for discussion (preferably via HCC)
6. Thalassaemia needing splenectomy
7. Patients needing rituximab/eculizumab for treatment of DHTR

MDT Process

Frequency

The video conference call will be held monthly to discuss cases referral 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 one hour and the day of the week will be pre-determined by the full MDT on a 6-12 monthly bases in order to ensure that specialist are invited well in advance to avoid clashes with other clinical responsibilities.

Specialist composition

The multi-disciplinary team (MDT) will consist of professionals from a core panel representing all the Haemoglobinopathy coordinating centres (HCC) across the country representing all professional groups involved in the care of patients with disorders described with the specialist haemoglobinopathies services – sickle cell disease, thalassaemia and rare 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 representative will not be invited at these meetings. In order to protect the clients confidentiality the discussion will take place using a secure communication medium either encrypting zoom conference or using a secure ‘blue jeans’ medium. 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 for emergency response and mailed to the relevant specialist on the database. 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 calls

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.. ,

Report to the referrer shall be written using a template response, which may be reviewed from time to time. The NHP shall endorse these reports

5. 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.

6. Declaration of interests

All members will make a formal declaration of interests which will be made publicly available (? On the website). 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.

NHP Structure and Key Relationships

