

National Haemoglobinopathy Panel Update

Professor Baba Inusa chaired the first NHP Inaugural business meeting held on 13 February which combined the discussion on business and MDT processes. This was a very successful fruitful meeting, which had a high level of attendance. We were able to discuss the plans for the next 6 to 12 months, the strategic priorities of the NHP and HCCs in year 1, programme of activities for the NHP and a number of documents which were in progress at that time i.e. TOR, referral criteria, TCD and technology platforms for the MDT videoconference etc.

Terms of References and MDT template

Following the meeting on the 13 February 2020 we now have a fully executed:

1. NHP Terms of Reference
2. MDT core Panel membership
3. MDT proforma

Technology/Communication

Technology has been a critical point of focus in driving the mobilisation plans. We have consulted regularly with the HCCs to discuss and validate our proposed use of technology and the Interim NHP chair, Baba Inusa has led on the development of new technologies developed to support the NHP.

The modes of technology outlined below will be managed by the NHP coordinator, under the direction of the NHP chair, and supported by the IT and communications experts of KCH, GSTT and KHP.

1. A KHP NHP SharePoint site has been up and functional since 2019, where the teams can access and store files. In light of the COVID-19 pandemic we have created a separate folder, with restricted access which is currently in use by NHP/HCCs Covid-19 leads for communication and dissemination of information.
2. A nhs.net secure share point is currently being developed and membership will consist of all HCCs and SHT. Membership is by invitation only. The site will host a number of materials, processes and documents i.e. MDT minutes, MDT process, update on clinical guidelines and on new therapies etc.
3. For the last 6 months we have been using Zoom video conference as a tool to have fortnightly calls with the working group and have also implemented a backup function with bluejeans, which is a digital platform for virtual communications similar to Skype, Zoom and TEAM.

Virtual Meetings

We are currently in the process of arranging a date for our first MDT Videoconference which will take place in late April. All MDT meetings will be hosted virtually, including our quarterly NHP business meetings, enabling participation from across the country, ensuring equity of access.

We are currently in the process of collating nominations for the MDT videoconference panel and email MDT. We are also pulling together the biographies of colleagues who have expressed an interest to be part of the email MDT advice panel. The biographies will detail their experience and expertise. The MDTs will be administered by the NHP coordinator and facilitated by the NHP chair.

We have finalised the MDT referral process and proforma template which has been agreed and circulated to the members.

We will continue to use videoconference (zoom) and teleconference facilities to enable participation, supported by a secure SharePoint site to facilitate the submission and review of relevant meeting documentation, log MDT cases and to store TCD quality assurance, mortality and morbidity data. Protocols will be established to determine controlled access to the SharePoint site.

We have just recently set up a secure nhs.net email account which will be used by the NHP chair and coordinator to manage referrals to the MDTs.

Social Media

We are currently discussing the use of social media, such as WhatsApp, Twitter, as a communication tool, to communicate upcoming training events and to promote service improvement and best practice. We will nurture an engaged network through regular posts, encouraging users to their share news and provide input into discussion. As an example, the NHP/HCCs COVID-19 have recently set up a WhatsApp group to discuss and share information.

Generic emails have been created

1. 2 weeks ago we created and rolled out the NHP MDT referral email address gst-tr.haemoglobinpanel@nhs.net.
2. 2 weeks ago we created and rolled out the South East HCC leaders – gst-tr.southeasthcc@nhs.net. Members will consist of Moji, Jo, David, Subarna (peer review) and Baba.

Website/ Logo

1. We are pleased to announce that the website domain has now been purchased: www.nationalhaempanel-nhs.net
2. We are also pleased to announce a NHP Logo has been commissioned and is now in use which you will see displayed in the header of this document.
3. The website is currently under construction. The NHP website will serve as the primary platform to publicise and support the work of the NHP. It will:
 - Publicise training events and conferences
 - Host the referral criteria and proforma for the MDTs
 - Host a depository of clinical guidelines, patient information and training materials

- Host information on innovative therapies and active research trials

MDT/ COVID-19 meetings

The NHP/HCC umbrella has been a timely development that has brought the family for thalassaemia and sickle cell disease together to work across regions on a single platform that has seen three major Covid-19 meetings leading a joint up approach. Key advice now covers sickle cell disease, thalassaemia and rare anaemias. The Covid-19 panel is aimed at bringing together clinicians together with NHSE/PHE. However patients are not participating on this panel even though there is patient representation on NHP and CRG it has been decided to make it a professional panel. Thanks to Jo for leading this piece of work and for Priscilla for her administrative expertise.

Significant developments include the coordination of advice, data collection, research and therapies especially in light of Covid-19 and beyond.

Highlights

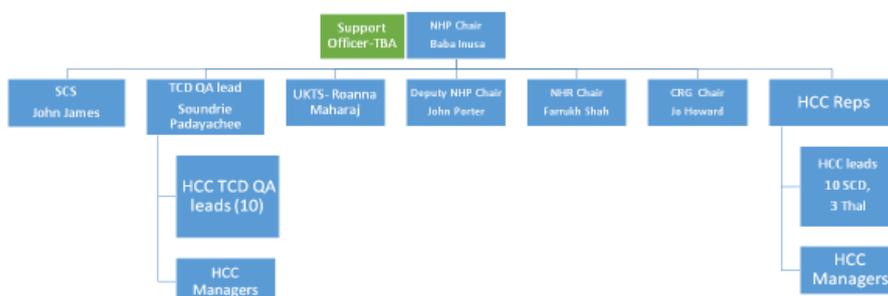
1st MDT will take place in April, information has now been sent.

Email panel is being assembled and biodata of prospective panellists is being collated.

Future appointments

1. NHP Operations Support Officer to be appointed April 2020
2. Permanent NHP Chair.

We have made quite a bit of progress which is with the combined support of Priscilla Douglas, Bijal Shah and Jo Howard.



Recruitment

NHP Chair

Expressions of interest for a permanent NHP Chair was sent out to the KHP Partnership Organisations. Interviews were due to be held in April however in light of the COVID-19 pandemic, there has been a shift in priorities where all focus for each of the Trust is to respond to the rapid evolving demands of COVID-19. Therefore, we took the decision to postpone the Chair interviews. This will be reviewed again in the coming weeks.

NHP Operations Support Officer

This post went out to advert and we received a huge amount of applications. Similarly, we discussed whether to go ahead with the interviews or postpone. We have agreed to hold virtual interviews for this post on Tuesday 7th April rather than face to face. We are conscious that with HR checks and notice periods it is unlikely that the new person will start in the post for 2-3 months.