National Haemoglobinopathy Panel

Annual Report

2020/21

Professor Baba Inusa

November 2021

National Haemoglobinopathy Panel

Table of Contents

1. Introduction

This report provides a report of the implementation of the National Haemoglobinopathy Panel (NHP) and a review of the first full year of operation 1st January 2020 to 31st March 2021.

1.1 Implementation

In 2019, NHS England/Improvement sought to commission providers of specialised haemoglobinopathy services to create the provision of a new model of care, delivering specialist and non-specialist haemoglobinopathy services to adults and children and providing expert opinion and management for complex patients. Applications were invited for the National Haemoglobinopathy Panel (NHP), Haemoglobinopathy Coordinating Centres (HCC) and Specialist Haemoglobinopathy Teams (SHT).

Specialised Haemoglobinopathy Services -

NHS commissioning » Specialised haemoglobinopathy services (england.nhs.uk)

NHS commissioning » F05. Haemoglobinopathies (england.nhs.uk)

In June 2019, King's Health Partners (KHP - King's College Hospital NHS Foundation Trust (KCH) and Guy's and St Thomas' NHS Foundation Trust (GSTT)) submitted an application to host the NHP. The King's Health Partners steering committee comprised members Professor Jo Howard, Professor David Rees, Dr Moji Awogbade, Bijal Shah - Programme Manager (KHP), Priscilla Douglas - Project Manager (KHP), Andrew R Parker - Deputy General Manager (GSTT), Tuula Rintala - Service Manager (KCH), Cavette Castillo – Matron, Paediatrics (GSTT) and Professor Baba Inusa. In October 2019, KCH and GSTT were awarded the contract and between October-December 2019, the inaugural NHP was mobilized. KCH and GSTT were also jointly appointed as the Haemoglobinopathy Coordinating Centre and respectively as Specialist Haemoglobinopathy Teams for South East London and South East England.

1.2 Core Functions of the NHP

The NHP is the operational arm of the strategic leadership provided by the Clinical Reference Group (CRG) for NHS England/Improvement for the delivery of Haemoglobinopathy services. The core functions of the NHP are firstly to host the national MDT and secondly to realise the aims of NHS England and NHS Improvement.

The NHP seeks to provide overarching leadership, identify areas of strategic focus to improve the quality of haemoglobinopathy services across England and shape the respective programmes of work.

The core strategic functions of the NHP, as defined currently by the NHS England and Improvement (NHSE/I) Governance and Responsibilities document (attached) are summarised as: -

- To provide co-ordination of HCC leadership in alignment with the strategic requirements of the NHSE/I and (CRG)
- To lead the delivery of the national MDT
- To produce outcome reporting on a quarterly basis
- To inform the CRG of emerging issues and themes
- To coordinate workforce expansion and educational provision
- To maintain information on trials and research
- To support the development of a Quality Assurance programme for stroke screening in sickle cell disease using Transcranial Doppler Scanning (TCD)

(Attachment 1 – NHP Governance & Responsibilities Document)

(Attachment 2 - A fully detailed chronology of the first year of operation)

1.3 NHP Organisational Structure

The Chair of the NHP is appointed from the host HCC and is a co-opted affiliate member of the Haemoglobinopathies CRG. In June 2020, Professor Baba Inusa (Evelina London Children's Hospital, part of Guy's and St Thomas' NHS Foundation Trust) was appointed to the role.

NHP Business Operational Meetings

The NHP service is governed by business meetings, scheduled twice-yearly since inception, with membership of this group comprised of clinical leads representing every HCC, clinical representatives from multi-disciplinary fields (including nursing, pharmacy and psychology), and patient and public voice representatives currently represented by the national societies for sickle cell and thalassaemia and rare anaemia patients.

(Appendix 1 – Business Operations Membership)

NHP Multi-Disciplinary Team Meetings (MDT)

The NHP delivers monthly MDTs to support the management of complex cases and decision making around access to novel and high cost treatments. The NHP Core Panel Members represent clinicians from every HCC, across multiple fields and include clinicians with particular specialist expertise. The MDT panel meets by video-conference on a monthly basis and provides an email MDT process to enable the review of urgent or immediate cases requiring access to the NHP's clinical specialists. The NHP retains contact lists for additional clinical input from specialties outside of haematology, so that comprehensive review can be undertaken of the most complex cases.

(Appendix 2 – NHP MDT Membership – Video-Conference)

NHP Communications

A website www.nationalhaempanel-nhs.net was created to support the work of the NHP. It provides information including MDT schedule, news, meetings and event content, publications including updates from research, and new treatment horizon scanning. The NHP also has a twitter account @PanelNational. The NHP continues to encourage ongoing engagement and the promotion of matters of interest to the haemoglobinopathy and rare anaemia community at a national level via social media platforms and via regular ongoing engagement with all HCCs, SHTs and LHTs across England and colleagues across the United Kingdom.

NHP Reporting

The NHP provides regular reporting as determined by NHS England/Improvement and the CRG. Currently this includes the publication of a full Annual Report and regular Quarterly Reports. In addition, the NHP conducts reviews distributed across the HCC network to review themes and issues arising. As a result, the NHP can provide both formal progress reporting and responsive feedback on matters of national interest.

2. Multi-Disciplinary Team Meetings

2.1 MDT Framework

The monthly NHP MDT meetings support the management of complex cases. The MDT also provides national expert opinion on cases requiring consideration of novel and/or high cost treatments such as Bone Marrow Transplant (BMT) and Advanced Therapy Medicinal Products (ATMPs). The NHP MDT provides a national platform to support equitable access of care across the country.

The MDT involves the following people:

- NHP Chair and/or Deputy

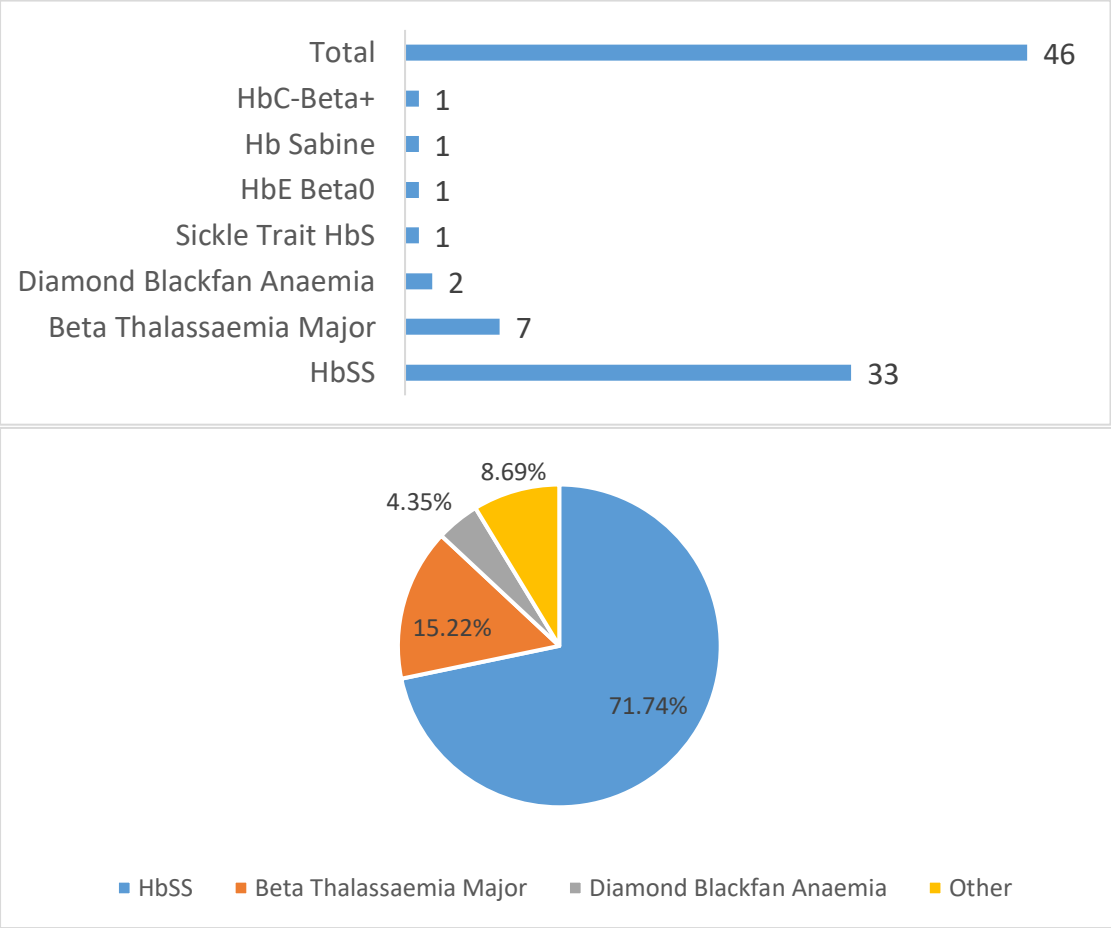
- Experts in specific disease/treatment areas such as Rare Inherited Anaemias, Thalassaemia, Paediatric Sickle Cell Disease, Adult Sickle Cell Disease, Blood Transfusion, Stem Cell Transplant, and Gene Therapy
- HCC Clinician(s) from each HCC
- Referring clinician
- Pharmacist
- Psychologist
- Nurse specialist
- Invited experts as required e.g. specialists representing Neurology, Cardiology, Chronic Pain, Nephrology, Hepatology, Respiratory, Urology, Ophthalmology, Orthopaedics, Fertility, Endocrine and Metabolic Disease.

2.2 MDT Cases

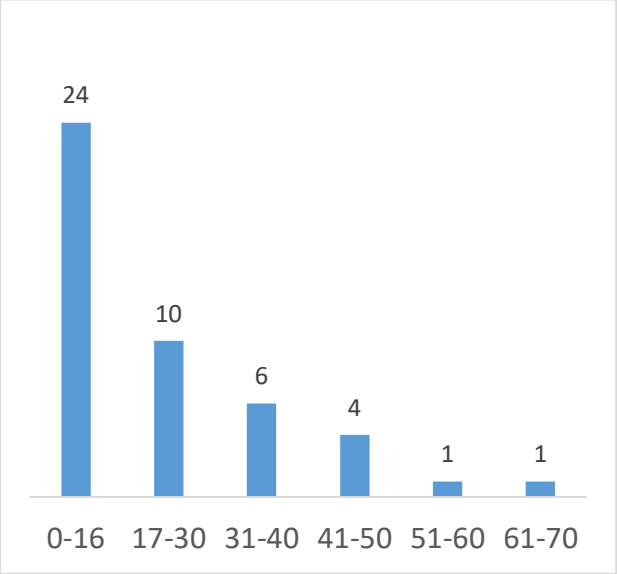
The NHP MDT panel met on a monthly basis, commencing in April 2020, and reviewed 46 cases, with referrals received from SHTs/HCCs across the country. A full analysis of the cases is shown in section 2.3; the majority were questions related to bone marrow transplantation and blood transfusion.

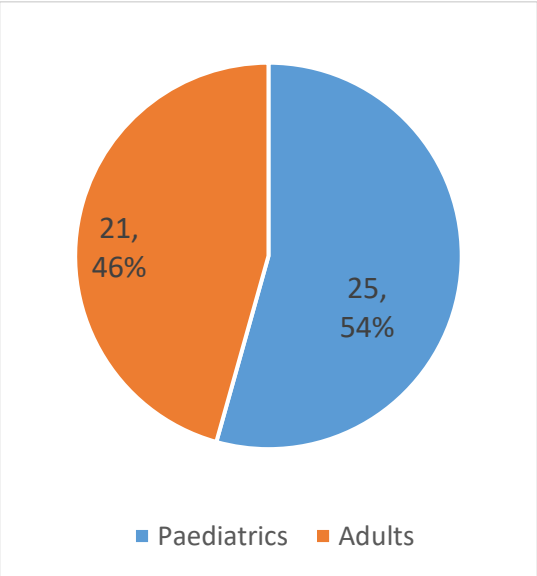
2.3 MDT Outcome Data & Analysis

1. Cases by primary diagnosis

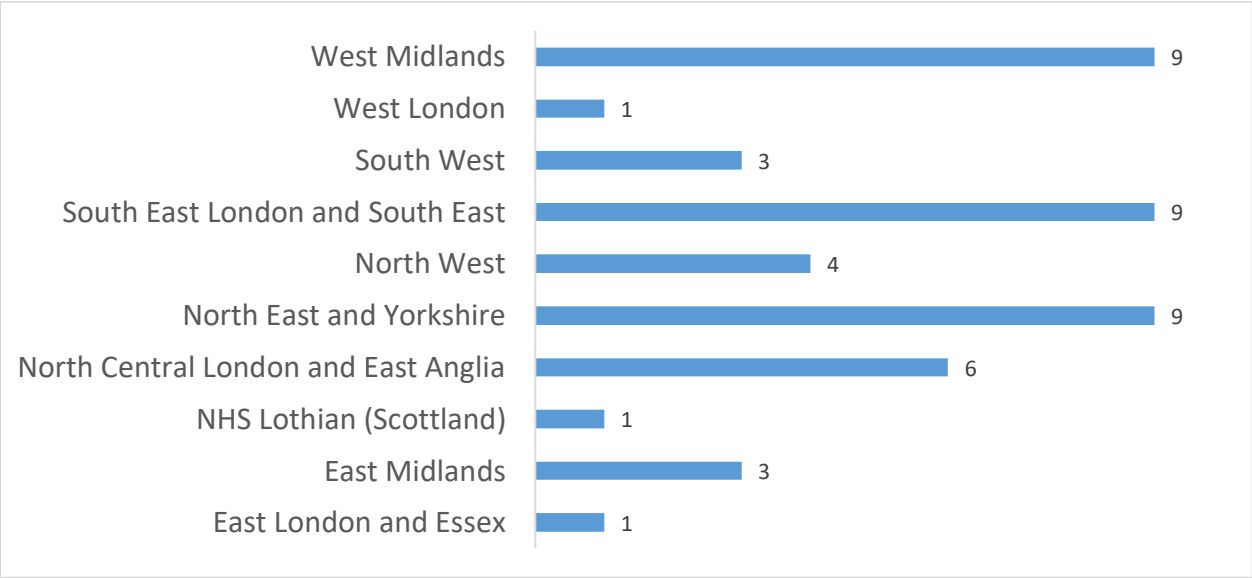


2. Age distribution of cases

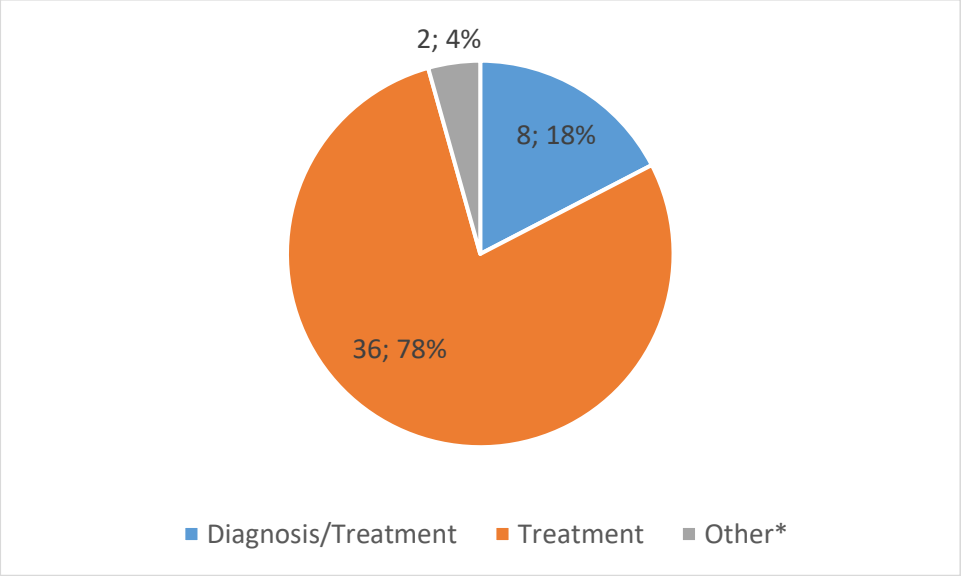




3. Referral Sources

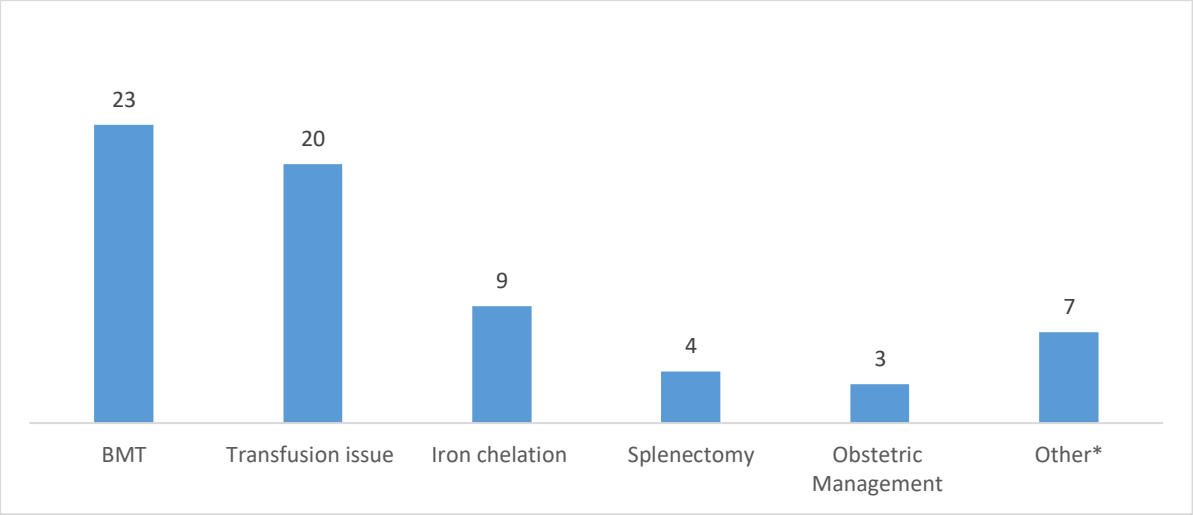


4. Reason for referral



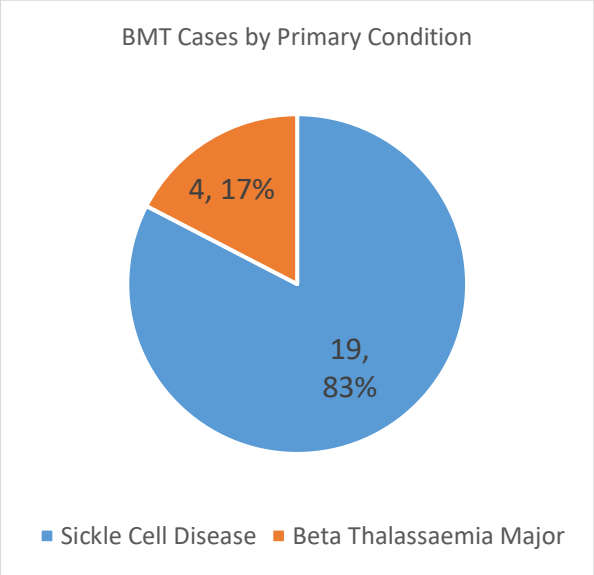
*Other: IRF referrals and Fertility option and mitigating risk in context of transfusion referrals.

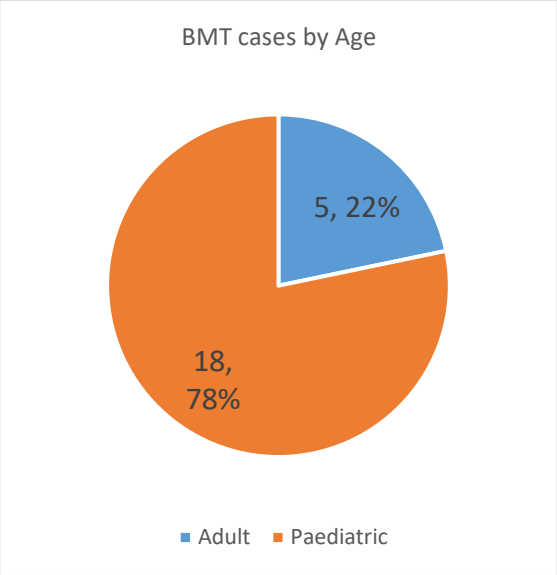
5. Case Themes

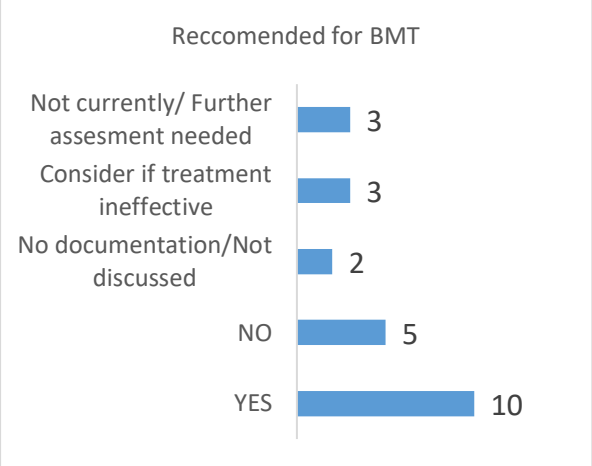


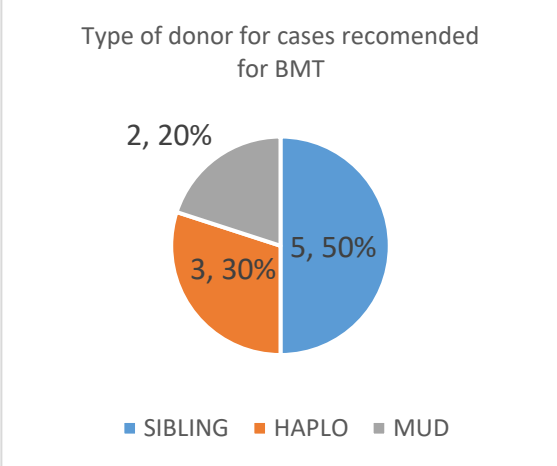
* Other new/alternative therapies: Arginine, Gene Therapy, Luspatercept, Natrox, Ruxolitinib, Toclizumab, Voxelotor.

Cases Referred for BMT









6. Case Review and Recommendations

At the time of production of the Annual Report, 30% of cases had received recorded 6 month follow-up feedback from the referring consultants. No feedback was available for 2 patients. The NHP is awaiting the updates requested for the remaining cases.

7. MDT Survey

In order to improve the NHP MDT process, a survey was conducted of NHP members and contributors in October 2020.

(Appendix 3 – NHP MDT Survey)

3. Trans-Cranial Doppler (TCD) National Quality Assurance Programme

Throughout the past year, the NHP has supported the development and reviewed progress of the Trans-Cranial Doppler (TCD) screening Quality Assurance Programme. The programme is led by Dr Soundrie Padayachee, with regional TCD Leads representing each of the HCCs.

The progress of the programme is documented in the TCD Annual Report attached and content from the most recent 2021 progress report is included below.

(Attachment 3 – TCD QA Annual Report)

3.1 TCD QA Progress Report (November 2021)

The National QA Programme for TCD screening aims to improve standardisation and delivery across the Network. To achieve this some responsibility was devolved to local HCC TCD leads. Progress has been made in the following areas:

1. Regional TCD leads have been appointed at all 10 HCCs and are now responsible for the TCD practice in their HCC, including staffing the TCD programme and ensuring QA standards are met. (Table)
2. There is clearer oversight of the provision of TCD screening across the Network
3. TCD Standard Operating Procedure has been approved by the TCD panel & Regional TCD leads
4. The Quality Assurance programme is in progress with questionnaires being returned for
    a. TCD Instrumentation
    b. TCD Practitioners scanning portfolio (scan numbers and STOP distribution)
    c. Competent practitioners have been added to the National register
5. TCD training at the National centres has not restarted post-pandemic but has been delivered locally by Regional TCD leads. Work is in progress to enable this programme to be delivered virtually or face-to-face. This will be combined with a competency process to be delivered by Regional TCD leads and overseen by the TCD Panel Lead.
6. There has been significant progress with the TCD dashboard of the National Haemoglobinopathy Registry. The dashboard was developed following testing and review by the TCD Regional leads, and went live in June 2021. Nearly 1500 TCD scans have since been entered on the NHR. Data entered includes TCD velocities, STOP categories and non-diagnostic scans. Not all centres have entered data but we are working to increase the uptake.
7. QA & the NHR TCD Dashboard: Work is currently in progress to develop a QA report using TCD data entered on the NHR. This includes information on practitioner scan numbers, STOP classifications and velocity ranges. The velocity data can be used to identify any systematic variations that might indicate over or under-estimation of velocity, this would have a direct impact on STOP classification. An advantage is the considerable labour saving for Regional TCD leads if the TCD QA data can be extracted from the NHR TCD data return.

Summary

The primary aim of the National QA Programme - to ensure that TCD performed by either a haematologist or clinical scientist is performed, interpreted and reported correctly - is being addressed. Work is in progress to interrogate the NHR data to determine variability at Centre and Practitioner level. This will allow us to identify potential sources of error and to implement corrective measures.

3.2 TCD Regional Leads 2020

NATIONAL SCD QA PROGRAMME - TCD REGIONAL LEADS 2020				
PANEL LEAD	Professor Baba Inusa, Chair National Haemoglobinopathy Panel Meeting			
TCD PANEL LEAD	Soundrie Padayachee			
SCD HCC	**HCC LEAD**	**HOSPITAL**	**REGIONAL TCD LEAD**	**PRACTITIONERS**
NORTH WEST	Kate RYAN & John GRAINGER	ALDER HEY	Laurence ABERNETHY	Julie SMITH
		MANCHESTER UNIVERSITY	Vivian TANG	Rob HAWKES
NORTH EAST & YORKSHIRE	Josh WRIGHT & Emma ASTWOOD	LEEDS INFIRMARY	Anne-Marie JEANES	
		SHEFFIELD TEACHING HOSPITALS	Ashok Raghavan	
EAST MIDLANDS	Amy WEBSTER & Ryan MULLALY	UNIVERSITY HOSPITALS OF LEICESTER	Joanne WALKER	Hannah LINES
		UNIVERSITY HOSPITAL OF NOTTINGHAM		Richard SIMPSON
		UNIVERSITY HOSPITAL OF DERBY & BURTON		Robert DINEEN
		NORTHAMPTON GENERAL HOSPITAL		
		KETTERING GENERAL HOSPITAL		
WEST MIDLANDS	Mark Valengi & Shiva PANCHAM	COVENTRY & WARWICKSHIRE	Adam LOVICK	Stephanie WARR
				Asif DILSHAD
EAST LONDON & ESSEX	Banu KAYA & Paul TELFER	BARTS HEALTH	Paul TELFER & Banu KAYA	
		ROYAL LONDON		Naavalah NGWA-NDIFOR
		ROYAL LONDON		Kate CRAWFORD
		QUEENS HOSPITAL, WHIPPS CROSS		Sherif SADAK
		NEWHAM UNIVERSITY		Koganti RAMAKOTAIAH
SOUTH EAST LONDON & SOUTH EAST	Jo HOWARD	KINGS COLLEGE HOSPITAL	Colin DEANE	Ben FREEDMAN
				Annette QUIN
				Helen DIXON
				Emily HILLIER
				Dorata KOLADE
		GSTT & EVELINA CHILDRENS HOSPITAL		Nicholas THOMAS
				Andrew ARNOLD
WEST LONDON	Mark LAYTON & Josu DE LA FUENTE	ST. GEORGES	Mark YOUNG	Fabrizio D'ABATE
				Veni RAMACHANDRAN
		IMPERIAL COLLEGE	Kirstine LUND	Carlo PINHO
				Sophie CONNELLY
				Emma PARTRIDGE
				Natasha STREVENS
				Mo KO WIN
		NORTHWICK PARK	Nazia SAEED	Kamran MODARESI
				Veronica SAGAYARAJAH
NORTH CENTRAL LONDON & EAST ANGLIA	Emma DRASER (Andrew ROBINS & Fenella KIRKHAM)	UCLH & WHITTINGTON	Fenella KIRKHAM	Fenella KIRKHAM
		NORTH MIDDLESEX (ADDENBROOKS)		Edith AIMIUWU
				Rogers KALENDE
				Ibrahim ISMAIL
				Marilym ROBERTS-HAREWOOD
WESSEX & THAMES VALLEY	Wale ATOYEBI & Amrana QURESHI	OXFORD (MILTON KEYNES)	Sara MAZZUCCO	Kaye PLATT
		SOUTHAMPTON	Tony BIRCH	Ismail Elbeshlawi
SOUTH WEST	Sanne LUGTHART Michelle CUMMINGS	BRISTOL	Teresa ROBINSON	Nonie GUARIN
				Alex WEBB

4. Clinical Reference Group for Haemoglobinopathies

4.1 Clinical Reference Group Update Report – Professor Jo Howard

The role of the Clinical Reference Groups (CRGs) is to:

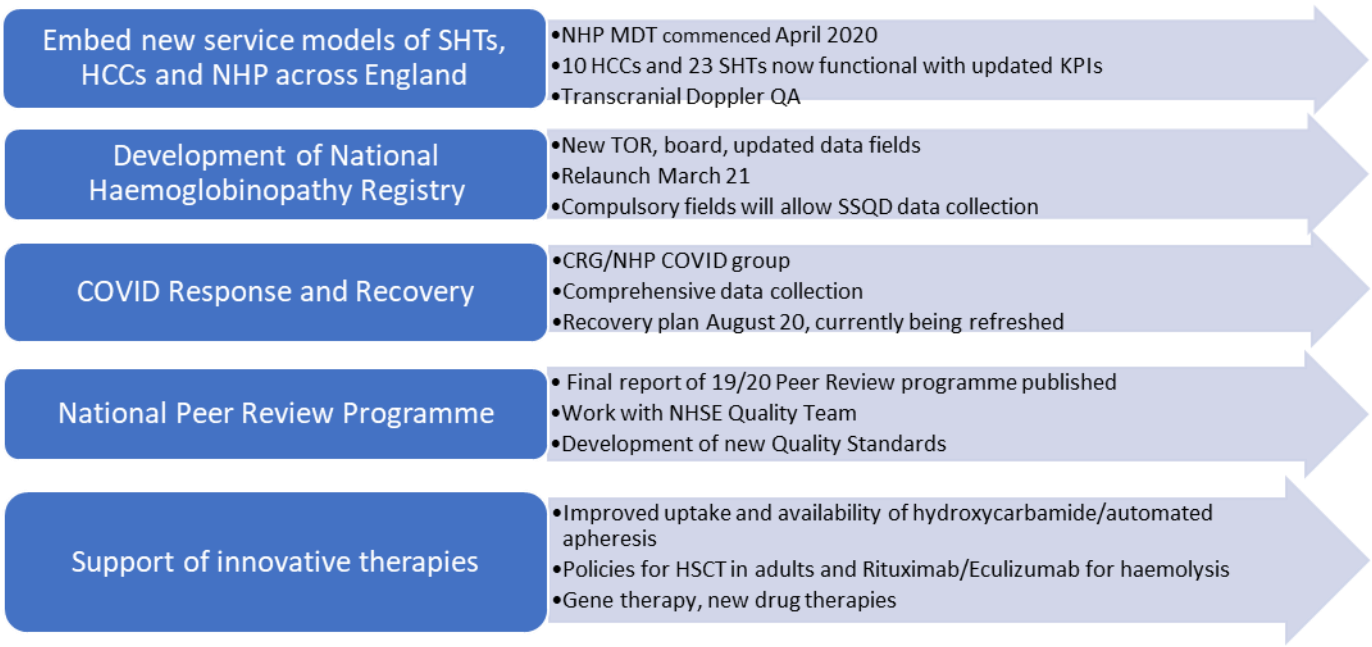
- Offer specific knowledge and expertise to advise NHSE and NHSI on best ways specialised services should be provided
- Lead on development of clinical commissioning policies, service specifications and quality standards
- Advise on innovation, horizon scanning, service reviews
- Guide work to reduce variation and deliver increased value
- Ensure that changes to commissioning of specialised services focus on the needs of patients and the public.

The clinical priorities of the Haemoglobinopathies CRG are:

- ❖ Clinical leadership to support the embedding of the new service model and National Haemoglobinopathy Panel
- ❖ Support of the delivery of revised National Haemoglobinopathy Registry.

The CRG provides an update of its work plan at the twice yearly NHP meetings.

The achievements of the Haemoglobinopathies CRG for the year 20/21 are displayed below.



5. UK Forum on Haemoglobin Disorders

5.1 Peer review 2018-2020 Summary – Dr Subarna Chakravorty

Introduction

Sickle Cell Disease (SCD) and thalassaemia are of increasing public health importance in the UK. Approximately 12,000 and 1000 thalassaemia patients currently reside in the UK and approximately 300 babies are born in England each year with a significant haemoglobinopathy. To ensure equitable access to high quality clinical care for all patients, several clinical guidelines for the care of adults and children with SCD and thalassaemia have been published and are regularly updated. Additionally, the UK Forum on Haemoglobin Disorders (UKFHD) have published healthcare Quality Standards (QS) for the care people with haemoglobinopathy. These standards cover all aspects of clinical care, including in-hospital and out of hospital care, and general, acute and specialist care. The QS also clearly outline roles of clinical commissioning and clinical networks in managing patients.

Three consecutive programmes of Peer Review have been conducted so far to ensure that services providing care for individuals with SCD meet the QS requirement and facilitate good experience of care for their patients. These reviews were executed by a clinical leadership team from the UKFHD with the assistance of the West Midlands Quality Review Service (WMQRS), which provided governance and support. The programmes were fully supported by patient groups at the development, execution and reporting stages of the programmes.

In 2018 the UKFHD has resolved to undertake a fourth review cycle to continue to build on its success in bringing about process change in haemoglobinopathy service delivery in the UK for patient benefit. The Quality Standards have been updated and WMQRS are once again the operational partners of this programme.

Several review models were discussed; balancing the need for careful assessment to ensure maintenance of satisfactory standard of care and the considerable resources needed to administer a fully visit-based Peer Review programme. The UKFHD approved a model based on self-assessment (SA) against QS followed by visits to selected services.

Principles of the approach:

1. The steering group (currently chaired by Dr Subarna Chakravorty) will have oversight of the programme and will meet sufficiently regularly (face to face and virtually) to allow good progress.
2. There are currently 33 adult and 33 children's centres to be included in the self-assessments and a sub-set of these selected for review.
3. HD Centres will initially be asked to submit a self-assessment (SA). All centres will be expected to take part.
4. The UK Forum will need to agree a process for communication of this programme and reach agreement with each centre lead clinician.
5. The SA will be based on the current WMQRS standards for Haemoglobin Disorders
6. WMQRS will develop a data collection pro forma.
7. WMQRS will develop a simple data collection tool (excel based) to allow submission and collation of responses.
8. The UK forum will agree a high-level series of indicators that define risk.
9. Indicators will give broadly equal weighting to patient voice/experience and clinical outcomes.
10. As a minimum, a multidisciplinary review team will consist of a patient, a Consultant and Nurse.
11. A scoring methodology will be agreed before data collection that allows centres to be stratified on a risk-based score. It should be noted that a previous review has taken place in 2016 and so a base line and improvement journey is already defined.
12. All centres will be expected to self-assess at the same time to create a clear profile of centres across the UK.
13. The steering group will be required to commit at least one day (possibly two days) to review the entire self-assessments at the same time and decide and agree the risk stratification and review plan.
14. The UK Forum will need to agree if centres being reviewed more than 12 months from their initial SA will be allowed (or encouraged) to reassess.
15. Those with the poorest scores will all be identified for review; those with higher scored will be sampled for review. The exact demarcation to be agreed, but it envisaged 3 groups. a. Group 1 – poorest score – all for review
b. Group 2 – middle scores – approx. 50% for review
c. Group 3 highest scores – approx. 10% for review.
16. WMQRS will lead a review programme overseen by the UK Forum to those identified centres with a peer review team of clinicians.
17. The forum will fund the programme costs through charging all trusts that are submitting self-assessment forms. Any shortfall in accounts will be covered by the UK Forum.
18. The UK Forum will request a copy of action plans from centres and seek assurance that progress is being made. The Forum is not accountable for progress of the plans.

Steering Group

The steering group will comprise doctors, nurses, psychologists and service users /representatives. Beside the chair and the 4 members of the core SG (KH, RKA, ED and MV), previous Peer Review leads have been invited to the SG and have accepted (BK, JW, AY, KR). Additionally, two psychologists (Heather Rawle and Helen Demarco) will job- share. Four nurses – Maureen Scarlett, Louise Smith, Connie Harewood and Sandy Hayes) are also part of the SG. It is expected that the SCS and UKTS will have SG representation as before.

The SG will meet F2F and review the SA returns. All visit reports will be finalised after a SG teleconference. The SG will be quorate if at least 2 clinical leads, 2 nurses, one service user and one psychologist are in attendance.

The proposed stream and timelines for the latest review cycle:

Updates QS circulated to trusts:	March 2018
Initial meeting with WMQRS to discuss Peer Review models	April 2018
Sign –off of Self-assessment matrix	September 2018
Selection of Peer Review Steering Group nursing and psychology members	September 2018

UK Forum and WMQRS to jointly write to clinical leads informing them about forthcoming reviews	September 2018
WMQRS bill trusts and obtain expression of interest in participating in reviews	October 2018
Trusts given 8 weeks' notice to upload SA forms	Dec 2018
SA returns obtained over a 2-week period	Feb 2019
WMQRS reviews and finalises reviewer training	Jan- March 2019
SG meet to discuss SA returns and choose review visits	March 2019
Review visits start	April 2019
SG meet via teleconference once a month to discuss and sign off reports	
Final F2F SG meeting to discuss overview report	January 2020
Good Practice Sharing event hosted by UK Forum	May 2020.

Summary of the 2020 findings:

- Shortage of specialist medical, nursing and psychology staff threaten the future viability of some services
- Patient voices still not heard
- Often seen as poor cousin to oncology
- New commissioning structure has injected much needed funds for new staff.

Next Steps:

- Align QS to new commissioning arrangements
- Liaise with NHSE to conduct future reviews
- Aim to train future generation of CNS and consultants
- Continue to advocate for our patients and improving care.

6. NHR – National Haemoglobinopathy Register

The NHR rebuild work was started in Spring 2020 and completed in September 2020. Four sites started testing the new NHR in October 2020 and feedback from those sites allowed the optimisation of the NHR platform. The initial build had been web based in the Azure cloud but due to compatibility issues in linking with the Newborn screening programme, the build was shifted into the N3 network to ensure the system was fully compatible.

The Interim steering committee transitioned into the full steering committee in September 2020. Patient representatives were interviewed in August 2020 and 4 are now active members of the steering committee. A Data analysis and research group were developed as a subcommittee of the Steering committee to ensure that data entry queries and research documents were developed to support the reporting aspects as well as support more rapid data related decision making. All the patient representatives are part of the DARG group.

Once testing was completed, the NHR was made live for all sites simultaneously. Since the NHR went live many updates have been made to ensure that the NHR data collection was fit for purpose. The NHR data fields were adjusted to ensure that the SHT dashboard could be collected from data on the NHR but the HCC metrics which were provided in January would be more complicated to collect. Build on the TCD data collection started in February 2021 and was finally completed in June 2021.

7. Covid-19 Pandemic

7.1 Organisational Structure - NHP, HCC Networks and Covid-19

The NHSE framework of NHP, HCC and SHT centres were in the midst of set up when the Covid-19 Pandemic was declared in March 2020. This gave the haemoglobinopathy community the ability to react rapidly and provided us the mechanism to set up a national group under the NHP to respond to Covid-19 involving every HCC in England. We were then able to initiate national data collection, receiving anonymised data on every patient with a haemoglobinopathy whether proven or suspect Covid-19 infection. This uniquely complete set of data provided very valuable information on outcomes in this population and demonstrated the value of the new structure of service provision. We have been able to highlight the high quality NHS service to protecting vulnerable groups during Covid through scientific publication in peer reviewed journal; Roy N et al British Journal of Haematology, 2020, 189, 635–639. We were able to rapidly set up and obtain comprehensive real time national data on COVID suspected and confirmed cases in SCD, thalassaemia and rare anaemia cases via the structure of the NHP, HCC leads and commissioned networks. Preliminary data reports were submitted to the European Haematology Association Scientific Conference and accepted as late breaking oral presentation on 14th June, 2020 reflecting the importance of this data.

7.2 National Data Collection – Professor Mark Layton

The Covid-19 pandemic has brought challenges of an unprecedented scale to the NHS. As a high risk group, haemoglobinopathy patients were prioritized and due to their vulnerable status many have spent much of the past year shielding. To monitor the impact upon our patient cohort, the Haemoglobinopathies Covid Group was established by the CRG and facilitated via the NHP. Professor Mark Layton and the team at Imperial College Healthcare NHS Trust led an initiative to develop national data collection throughout the course of the pandemic, which continues to track the course of Covid-19.

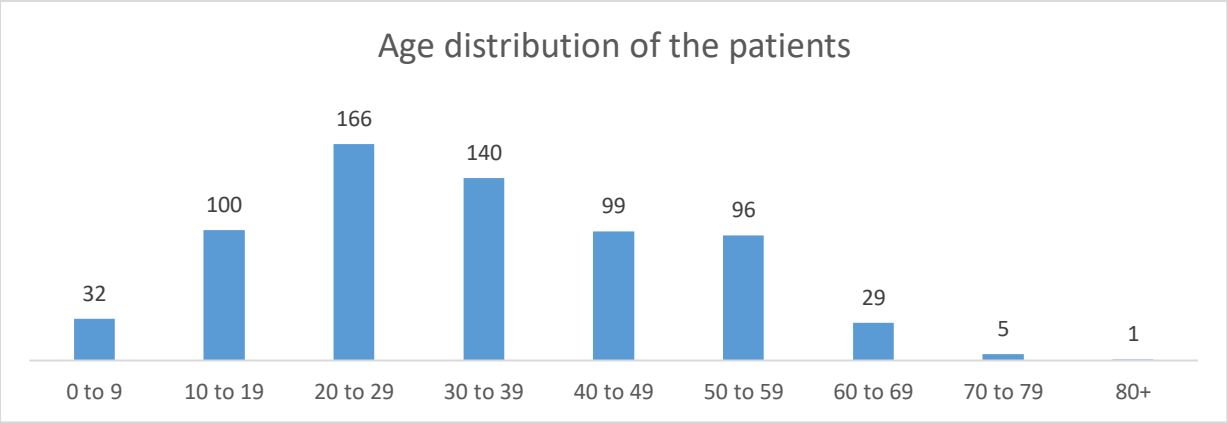
7.3 Data Summary

(Note - data snapshot from March 2021)

At this point, 668 positive Covid-19 cases had been reported by eleven HCCs. The youngest patient was under a year and the oldest one above 80 years old. The highest numbers (25%) of the covid positive patients were from the 20-29 years group and the lowest one from the oldest (80 plus) group.

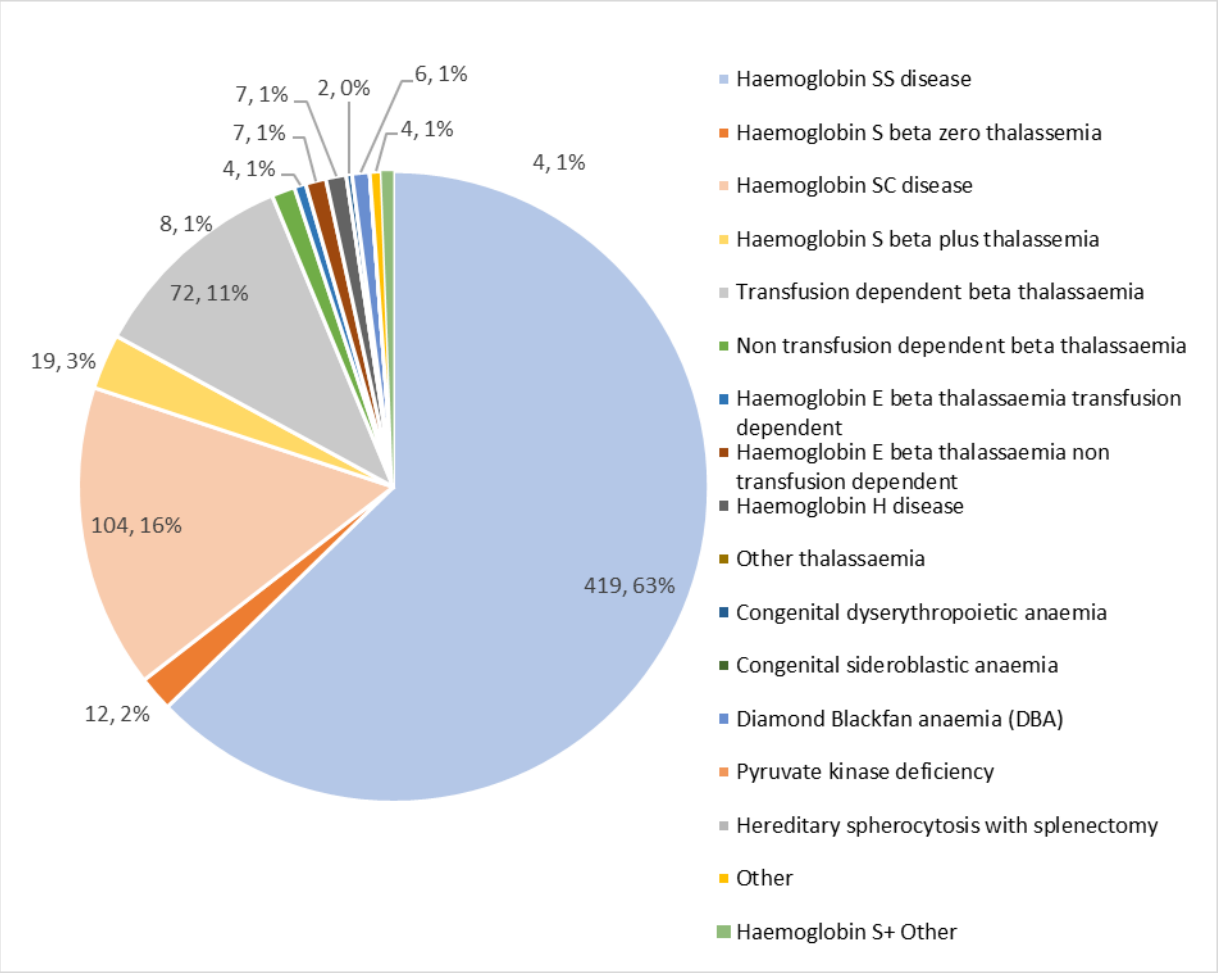
HCC	No. of Cases	Centre	No. of Cases
South East London and South East	239	Guy's and St Thomas	104
		Kings College Hospital	81
		University Hospital Lewisham	15
		Croydon Health Services NHS Trust	14
		Evelina Children's Hospital	13
		Darent Valley Hospital	4
		Medway Maritime- Adult and Paediatric	3
		Queen Elizabeth Hospital, Woolwich	3
		Maidstone and Tunbridge Wells NHS Trust	1
		Princess Royal University Hospital	1
East London and Essex	105	Barts Health	78
		Homerton Hospital	19
		Queens Hospital (BHR)	8
West London	95	Imperial College Healthcare NHS Trust	37
		St Georges Healthcare NHS Trust, London	31
		London North West University Healthcare NHS Trust	25
		St Helier University Hospital Trust	2
North Central London and East Anglia	71	The Whittington Hospital NHS Trust	39
		London University College London Hospitals	20
		North Middlesex	10
		Royal Free NHS Trust	2
North West	51	Manchester Royal Infirmary	44
		Royal Liverpool University Hospital	5
		Alder Hey Children's Liverpool	2
East Midlands	37	University Hospitals Leicester	23
		Northampton General Hospital	9
		Kettering General Hospital NHS foundation Trust	2
		Nottingham University Hospitals	2
		Derby	1
West Midlands	27	Birmingham - City Hospital	12

		Birmingham Children's	6
		Coventry University Hospital	4
		The Royal Wolverhampton	3
		Gloucestershire Royal Hospital	1
		University Hospital Birmingham	1
North East and Yorkshire	15	Royal Victoria Infirmary, Newcastle upon Tyne	4
		Sheffield Teaching Hospitals NHS Foundation Trust	4
		Bradford Teaching Hospitals NHS Foundation Trust	3
		St James's University Hospital, Leeds	3
		Sheffield Children's Hospital	1
Wessex and Thames Valley	20	Oxford University Hospitals NHS Trust	9
		Milton Keynes Hospital	7
		Southampton University Hospital Trust	2
		Royal Berkshire NHS Foundation Trust	1
		Wexham Park Hospital	1
Wales	2	University Hospital of Wales	2
South West	3	University Hospitals Bristol NHS Trust	3



The most common phenotypes reported were Haemoglobin SS disease (63%), Haemoglobin SC disease (16%) and Transfusion dependent beta thalassaemia (11%).

Cases by Phenotype



52% of the patients required hospitalization. However, it is assumed that this ratio is heavily overstated, since there were also unreported cases, which were managed at home, and additionally unreported asymptomatic cases. The Covid19 related death rate amongst positive rare anaemia patients was 4% (25 patients). That increased to 8% amongst hospitalised individuals. There were no registered deaths amongst children.

There was no statistically significant association for gender (p=0.77) and only some between the severity of the disease (p=0.055) and the number of covid related deaths. However, strong evidence against null hypothesis (p>0.0001) suggests statistically significant link between age group and the death rate amongst PCR and antibody positive sickle cell disease patients.

	Alive	Dead	P-Value
Patient gender			
Female	232 (96.3%)	9 (3.7%)	0.77
Male	156 (95.7%)	7 (4.3%)	
Patient age (y)			
<10	21 (100%)	0 (0%)	
10-19.9	59 (98.3%)	1 (1.7%)	
20-29.9	104 (98.1 %)	2 (1.9%)	0.0001

30-39.9	78 (97.5 %)	2 (2.5%)	
40-49.9	58 (100%)	0 (0%)	
50-59.9	49 (87.5%)	7 (12.5%)	
>59.9	19 (82.6%)	4 (17.3%)	
Disease Severity			
Mild	89 (92.7%)	7 (7.3%)	0.055
Severe	299 (97.1%)	9 (2.9%)	

8. Patient and Public Voice Representation

8.1 Sickle Cell Society – John James OBE

The Sickle Cell Society's full report is included as an attachment; the opening summary of which is detailed below.

'This year has been continually busy, with COVID-19 being at the forefront of our minds, but this hasn't stopped the Society from engaging in a wide range of work with partners, including the National Haemoglobinopathy Panel (NHP).

Ensuring that people living with sickle cell have up-to-date guidance and support around COVID-19 has been a priority for us but we have also been working hard in other areas such as policy through our role as secretariat of the Sickle Cell and Thalassaemia All-Party Parliamentary Group.'

(Attachment 4 – Sickle Cell Society Article for NHP Report)

8.2 UK Thalassaemia Society – Roanna Maharaj

The UK Thalassaemia Society's full report is included as an attachment; the opening summary of which is detailed below.

'Due to the financial climate and failures within the NHS systems, many haemoglobinopathy services in England have evolved into becoming the "heart" of a functional person-centred healthcare model by redesigning the coordination of care and support provisions for individuals with thalassaemia and other inherited blood conditions by focussing on prevention, empowerment and proactive management in way that is a safe, effective, compassionate.

We are grateful for the new system in place in attempting consistency of care, support and accountability, in addition to the dedication of health care professionals who go out of their way to ensure their patients receive the best care as possible. However, as the system is new, there are a few areas of concern which have been identified by our membership.'

(Attachment 5 – UK Thalassaemia Society Report)

9. Bone Marrow Transplant and Novel Treatment

Adult Bone marrow transplant was approved December 2019 and the Service Specification recommends that patients should be discussed at the National Haemoglobinopathy Panel MDM before referral for haematopoietic stem cell transplantation (HSCT) to obtain constant and equitable referral patterns. This will ensure national review of all referrals for HSCTs.

The status of NICE investigation of new therapies on the horizon for 2020-2021 is detailed below.-

Product	Commercial	Company	Nice ID	Stage
Crizanlizumab	Adakveo	Novartis	1406	Committee meeting - 04/11/2020, expected publication 27/01/2021
Voxelotor	Oxbryta	Global Blood Therapeutics	1403	Appraisal on hold due to updated regulatory timing information from company
Luspatercept	Reblozyl	Bristol Myers Squibb (previously Celegne)	1554 for thalassaemia	Suspended 24/01/2020 due to company unable to provide evidence submission and will reschedule
Luspatercept	Reblozyl	Bristol Myers Squibb (previously Celegne)	1550 for MDS	Suspended 06/02/2020 due to company unable to provide evidence submission and will reschedule
Betibeglogene autotemcel	Zynteglo	Bluebird Bio	968	Committee meeting 1: 13/01/2021, expected publication: 24/03/2021

10. NHP and Haemoglobinopathy Coordinating Centres

During this initial year of operation, the NHP has developed established working relationships with the ten HCCs, all of whom participate in regular formal meetings (MDT, Business Operations Meetings) and ad-hoc meetings to discuss topics of national importance (e.g. BMT and Novel Treatments). In addition to regular feedback sessions at the Business meetings, the NHP has sought to survey HCC feedback on various matters across the year including education provision, funding and implementation challenges. At the UKFHD in November 2021, Professor Baba Inusa, NHP Chair presented a summary of the NHP's first year.

(Attachment 6 – NHP Lessons)

In March 2021, at the Business Operations Meeting, the HCCs provided updates as below: -

North West – (KR) – progressing well, action plan for 2021-22 produced. Well attended education meeting included business/governance sessions. Feedback on NHP MDT cases had been positive. Issues – nurse educator not appointed therefore training delayed. LHT engagement difficult to maintain, particularly as large HCC with low prevalence in some LHTs.

North East & Yorkshire – (KR) strong collaboration between NW & NE HCC. (JW – post meeting) - Established successful outreach Haemoglobinopathy service from Sheffield to Bradford (which was identified as a struggling service). Functional NEY MDT Joint educational sessions with NW HCC. Successful appointment of network manager and other key lead roles. Working with NHSBT to establish equitable access to apheresis services across a large geographical area with 3 SHTs and multiple small LHT services. Website under development.

East Midlands – (AW) – Manager and lead nurse in place. Work ongoing regarding operational issues. Educational events rescheduled for summer 2021. Engagement has been intermittent but consistent. Concern that Dr Mullally has left Nottingham, therefore clinical lead post vacant.

West Midlands – (SP) – Struggled with recruitment but recently appointed network coordinator and education post. Some educational activity has been delayed. Working on SLA. LHT engagement is OK. Thalassaemia MDT with East Midlands team is ongoing. Plans in place to move forward.

East London & Essex – (FO) – MDT established. Website under development. Business and educational meetings are planned for summer 2021. Work underway on data cleansing. Progress now accelerating.

South East London & South East (JH) – Progressing well – network business meeting last week, MDT monthly, guidelines group continuing to update, various education sessions with most recent +70 participants, SPR training day, audit (pain and hydroxy completed), website updated. Next six months focus is NHR/data collection, monthly reporting and focus on nursing education, psychology and establishment of patient group/involvement.

West London (ML) – Similar progress to SE London, guidelines group established, monthly MDT, adhoc emergency MDT also held. KA has set up PPV group which is increasing activity. JDF is leading research group. HCC is supporting various national initiatives including Covid and research group. KA added that the aim is to make PPV group as wide as possible to generate wider input and that nursing education is also progressing well.

North Central London and East Anglia (ED) – Similar position, collaboration with W London & Oxford team re Thal MDT. Nurse Educator has been covering clinical work, therefore educational work has not developed as hoped. Work ongoing re data and plan for 2021-2. Patient participation 'not quite there yet' but will be another area of focus.

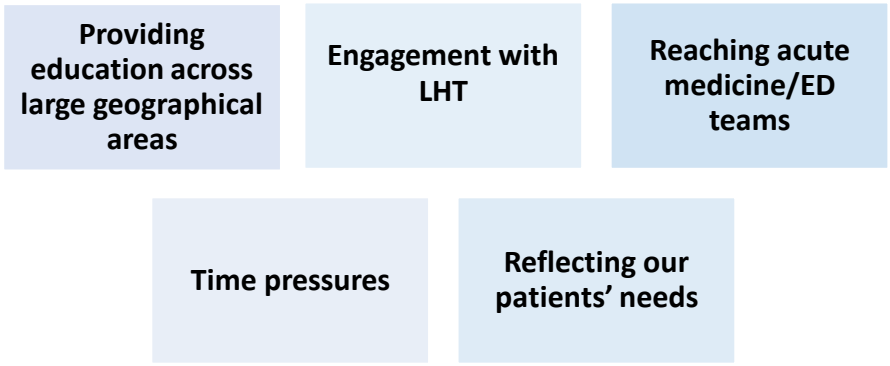
Wessex and Thames Valley (WA) – Generally Annual Review clinics underway virtually and well attended. Virtual support patient group meetings working well, including young peoples separate session. WA noted some difficulty engaging patients in prison and WA asked if that might be a point to review nationally. Nurse, HCC, MDT meetings under way. Clinical Psychologist appointed. Supporting sites across region. Service manager appointed.

South West (SL) – service and MDT coordinators appointed and specialised pharmacist in place, to review SOP and leading clinics. Education and business meetings held but issue with local engagement. SL noted that contacting sites individually had proven more successful. Focus on pain management audit, also transfusion audit. Patient Experience meeting was organised, from which psychology emerged as a focus area.

Thalassaemia HCC updates were covered within the HCC updates above, specific issues noted were regarding MRI imaging which was to be discussed subsequently.

In October 2021, the NHP collected further HCC feedback, a summary of the feedback is provided below: -

HCC Challenges in Delivering Education: -



- HCC suggestions have been many and varied – including – acute sickle management, pain management, transfusion, rare anaemia, mandatory undergraduate training, apheresis etc.
- Collation of resources on a central platform is widely requested.
- Role of NHP for education and training – to be further reviewed.
- Impact of work load upon education and training is a general concern.
- Education Action Plan proposal to be developed.

HCC Challenges in ensuring funding is accessible for expenditure on the development of Haemoglobinopathy services at HCC/SHT level. HCC specific examples include: -

- Requiring a business case for psychology support, despite this being an SHT specification.
- Data Manager seconded to another role / unable to 'access' funding for data manager.
- Sites receiving funding as an HCC and SHT expressed difficulty in being able to clearly define or draw upon the funds.

Whilst HCCs reported that NHSE had been helpful in reassuring local management teams that the funding was ongoing, it was felt that clearer messaging from NHSE would help to alleviate the issues that HCCs and SHTs were experiencing. There was also concern about future funding changes and potential impacts from moving from block to tariff contracts.

HCC Challenges in the recruitment and retention of staff. HCC specific examples include: -

- Difficulties in recruiting specialist haemgolobinopathy staff across all professional groups; exacerbated by the imminent retirement of senior colleagues.
- The impact of vacancies across services is impacting care – "a significant crisis – with multiple vacant posts".

HCC Challenges resulting from the Covid-19 pandemic. HCC specific examples include: -

- Increase in demand for services as a result of 'delayed presentation'.
- Peaks in demand for care, particularly inpatient care, have created significant difficulties.
- The lasting impact of the pandemic on the model of service delivery has resulted in some service providers feeling "overwhelmed" by the demands of new ways of working, e.g. virtual clinics.
- Haemoglobinopathy patients have lifelong conditions and their ability to access equitable, consistent care is sometimes potentially impacted by the post-pandemic pathways to care e.g. less face to face appointments. There is also concern that some patients have found this detrimental to their mental health and wellbeing.

11.Newborn Outcomes System – Emma Proctor

The NHP has liaised with the Newborn Outcomes System team from Public Health Commissioning & Operations, to support the nationwide implementation of this crucial system.

The newborn outcomes system is a web-based system for the referral of babies following a screen positive result in the newborn screening laboratory to clinical services

The objectives of the system are:

- support referral of screen positive infants from screening laboratories into treatment services
- improve patient safety by allowing users to view the status of patients along the care pathway
- alerts clinicians when important milestones are breached
- reduce duplication of data entry
- reduce manual chasing through automated alerts/prompts
- improve reporting so that you users' can monitor local performance and return annual data required to measure PHE standards 8 and 9
- improve quality and completeness of data to evaluate the programme – integrate with NCARDRS

On the 1st March 2021, all newborn blood spot laboratories had implemented the system across England.

Published – January 2022

12. Appendices

Appendix 1

National Haemoglobinopathy Panel - Business Operations Membership		
Name	**Region/Organisation**	**Organisation Type**
Amanda Hogan	Public Health England	PHE
Amy Webster	East Midlands	HCC
Andrew Parker	South East	Service
Baba Inusa	South East	HCC
Banu Kaya	East London (and CRG)	HCC
Ben Carpenter	NCL & EA & Adult BMT rep member	Rep
David Rees	South East	HCC
Emma Astwood	North East	HCC
Emma Drasar	North Central London and East Anglia	HCC
Emma Prescott (CNS)	North Central London and East Anglia	HCC
Farrukh Shah	North Central London and East Anglia	NHSBT
Gabriel Theo	UK Thalassaemia Society	Society
Heather Rawle	South East	HCC
Jo Howard	South East	HCC
Joe Sharif	North West	HCC
John Grainger	North West	HCC
John James	Sickle Cell Society	Society
John Porter	North Central London and East Anglia	HCC
Josh Wright	North East	HCC
Josu DelaFuente	West London	HCC
Kofi Anie	West London	HCC
Mark Layton	West London	HCC
Mark Velangi	West Midlands	HCC
Michelle Cummins	South West	HCC
Moji Awogbade	South East	HCC
Nandini Sadasivam	North West & Thalassaemia rep member	HCC/NHP
Nicole Paterson (CNS)	South West	HCC
Nkechi Anyanwu (CNS)	South East	HCC
Noemi Roy	W & TV & Rare Anaemias rep member	HCC/NHP
Paul Telfer	East London (and CRG)	HCC
Roanna Maharaj	UK Thalassaemia Society	Society
Ryan Mullally	NCL & EA (Previously East Midlands)	HCC
Sandy Hayes (ANP)	Wessex and Thames Valley	HCC
Sanne Lugthart	South West	HCC
Sara Trompeter	NHSBT	HCC
Sarah Kemp	South East / NHP	Service
Sharon Hodgson	NHSE & NHSI	NHS
Sharon Ndoro (CNS)	South East	HCC
Shivan Pancham	West Midlands	HCC
Soundrie Padayachee	South East	HCC
Sue Height	South East & Paediatric SC rep member	HCC/NHP
Tuula Rintala	South East	HCC
Victoria Potter	South East & Adult BMT rep member	HCC/NHP
Wale Atoyebi	Wessex and Thames Valley	HCC

Note - List as at October 2021, representatives are updated as required.

Return to main reference paragraph- App1

National Haemoglobinopathy Panel

Appendix 2

NHP MDT Video Panel	
Name	**HCC / Organisation**
Amrana Qureshi	Wessex & Thames Valley
Amy Webster	East Midlands
Baba Inusa	South East London & South East
Banu Kaya	East London & Essex
Ben Carpenter	West London
David Rees	South East London & South East
Emma Astwood	North East & Yorkshire
Emma Drasar	North Central London & East Anglia
Emma Prescott	North Central London & East Anglia
Farrah Shah	North Central London & East Anglia
Heather Rawle	South East London & South East
Jo Howard	South East London & South East
Joe Sharif	North West
John Grainger	North West
John Porter	North Central London & East Anglia
Josh Wright	North East & Yorkshire
Josu de la Fuente	West London
Kofi Anie	West London
Mark Layton	West London
Mark Velangi	West Midlands
Michelle Cummins	South West
Moji Awogbade	South East London & South East
Nandini Sadasivam	North West
Nicole Paterson	South West
Noemi Roy	Wessex & Thames Valley
Paul Telfer	East London & Essex
Perla Eleftheriou	North Central London & East Anglia
Sandy Hayes	Wessex & Thames Valley
Sanne Lugthart	South West
Sara Trompeter	North Central London & East Anglia
Shivan Pancham	West Midlands
Sue Height	South East London & South East
Tom Bullock	NHSBT
Victoria Potter	South East London & South East
Wale Atoyebi	Wessex & Thames Valley

Note - List as at October 2021, representatives are updated as required.

Return to main reference paragraph – App2

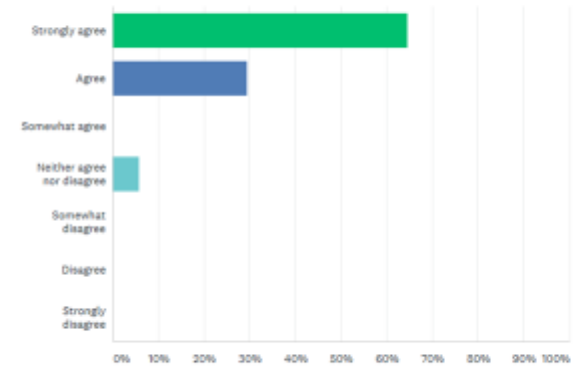
National Haemoglobinopathy Panel

Appendix 3 - NHP MDT Survey

NHP MDT Survey feedback

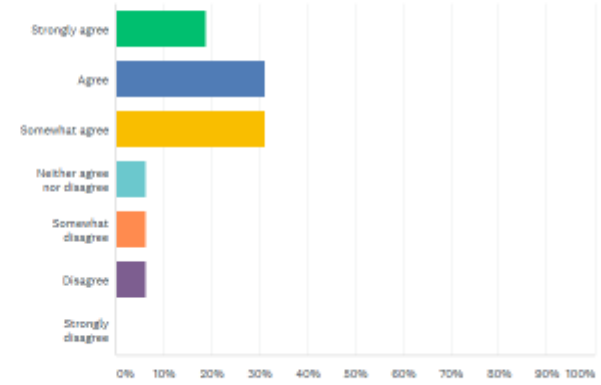
The MDT'S are relevant to my clinical specialty

Answered: 17 Skipped: 0



All members are actively and appropriately involved in discussion

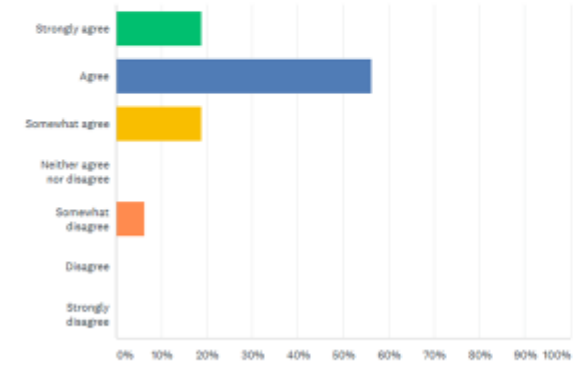
Answered: 16 Skipped: 1



NHP MDT Survey Feedback

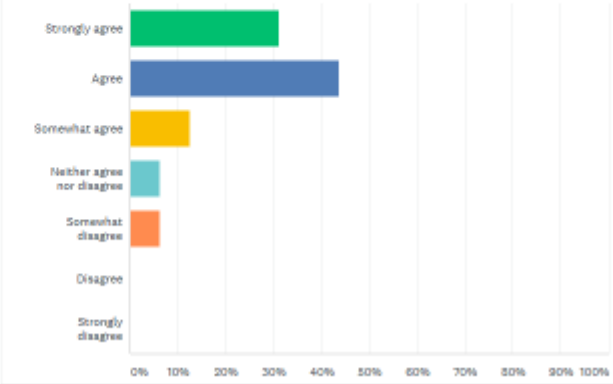
Members appear relaxed and respect each other

Answered: 16 Skipped: 1



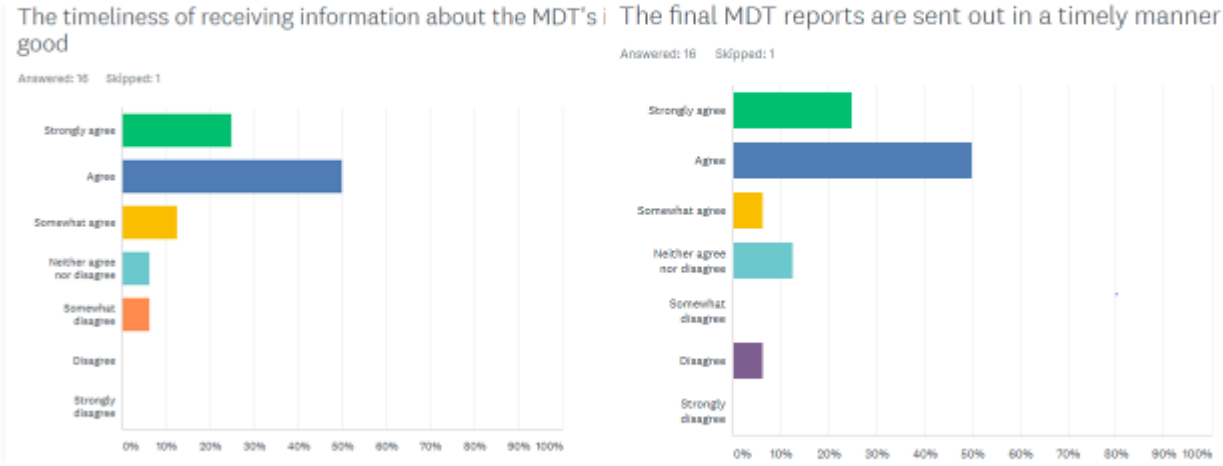
I am able to make comments or contribute to the discussion

Answered: 16 Skipped: 1



National Haemoglobinopathy Panel

MDT Survey Feedback



MDT Survey Feedback – Suggestions and Comments

What would help to improve your personal contribution to the MDT?

'Dedicated time in job plan.'

'A more structured format for contributions. A large number of individuals simply make comments when it suits them, sometimes when others are speaking.'

'A better facility for allowing people to speak in turn.'

'An awareness that not all have as much experience as others.'

'Consider separate paediatric and adult cases'

What one thing would you change to make the MDT more effective?

'Moderation of speakers to ensure all voices are heard.'

'Imaging review'

'Allow every individual with an interest in haemoglobin disorders to attend as observers'

'At present we are reviewing relatively few cases and discussions are sometimes over long.'

'External experts must be given time to make their contribution. Input only requested by small London group who are the only ones talking- for example asking a paediatric haematologist for input in stroke in 60 yr old SC patient with cardiovascular risk factors.'

Return to main reference paragraph – App3

13.Attachments

Attachment 1	NHP Governance and Responsibility	A1 - NHP Gov & Resp 21-22.pdf	Return to reference paragraph
Attachment 2	Detailed Chronology of First year of operation	A2 - NHP Chronology.docx	Return to reference paragraph
Attachment 3	TCD QA Annual Report	A3 - TCD QA Annual Report - Feb 21 PDF.p	Return to reference paragraph
Attachment 4	Sickle Cell Society Article for NHP Report	A4 Sickle Cell Society Article.pdf	Return to reference paragraph
Attachment 5	UK Thalassaemia Society Report	A5 NHP-UKTS v1.docx	Return to reference paragraph
Attachment 6	NHP Lessons From First Year	A6 NHP lessons from the first year.pptx	Return to reference paragraph