

Northwest England Sickle Cell Disease HCC

Annual Report

2022-2023

Manchester University
NHS Foundation Trust

Alder Hey Children's
NHS Foundation Trust

**The Royal Liverpool and
Broadgreen University Hospitals**
NHS Trust

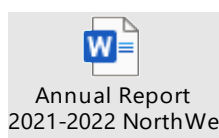
Distribution list:

- Manchester University NHS Foundation Trust
- The Royal Liverpool and Broadgreen University Hospitals NHS Trust
- Alder Hey Children's NHS foundation Trust
- Northwest England Sickle Cell Disease HCC Board Members
- North of England Specialised Commissioning Team, NHS England
- Local Hospital Teams, North West England

Reporting Trusts	Manchester University NHS Foundation Trust The Royal Liverpool and Broadgreen University Hospitals NHS Trust Alder Hey Children's NHS foundation Trust
Document Prepared By	HCC Network Manager
Date	June 2023

1. INTRODUCTION

This report is to demonstrate and highlight the activity conducted by the Northwest England Sickle Cell Disease Haemoglobinopathy Co-ordinating Centre (HCC) in line with the NHSE/I HCC service specification. The report details HCC activity during 1st April 2022 – 31st March 2023. Our previous 2021-2022 annual report can be read here:



The Northwest England Sickle Cell Disease HCC is a clinically led network consisting of a multi-disciplinary team, supporting both adults and children with haemoglobinopathies and the professionals/support networks caring for them. This HCC is made of 4 NHS hospitals: Manchester Royal Infirmary, Royal Manchester Children's Hospital, Royal Liverpool and Broadgreen University Hospitals NHS Trust and Alder Hey Children's hospital.

In addition to the specialist haemoglobinopathy teams in the Northwest, other key partnerships include local haemoglobinopathy teams, patient support groups, Manchester Sickle Cell and Thalassaemia Centre/Manchester Local Care Organisation, NHS England and other HCCs across England.

A key priority for 2022-2023 has been to respond to the All-Party Parliamentary Group (APPG) Report on Sickle Cell Disease; 'No One's Listening' Report. The following report details the specific actions and proposed workstreams regionally and for the individual SHTs within the region. Implementation of service changes and engagement across the region continued throughout 2022/23 and many actions completed by March 2023:



1.1 KEY ACHIEVEMENTS

1. Held first North West Sickle Cell Patient Event (12.11.2022)



Summary of patient feedback from event

2. Launch of HCC Website and Twitter Account

- i. <https://mft.nhs.uk/hcc/>
- ii. @HCC_MFT

3. Supported the NHSBT & MRI Collaboration to provide a Red Cell Exchange Adult Service Provision for North-West. [Read](#) how the service saved lives from Tiffany Salako, Sickle Cell Patient.



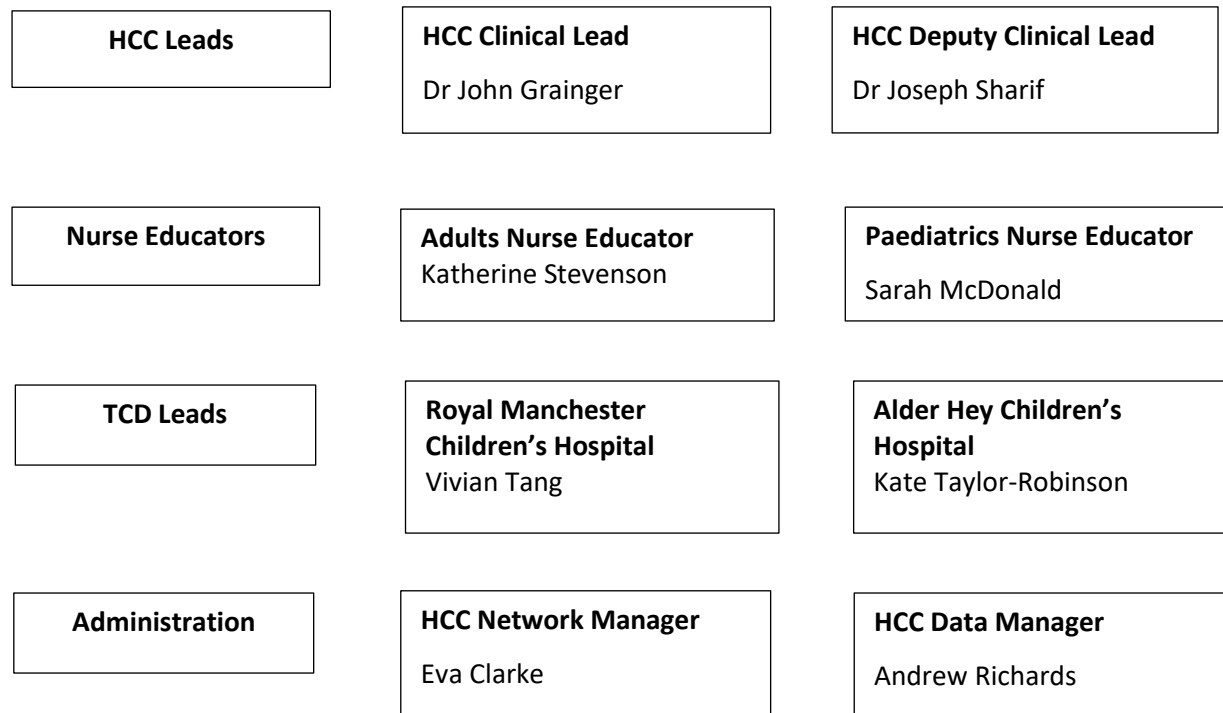
North West Automated Red Cell

4. Responded to All-Party Parliamentary Group (APPG) Report on Sickle Cell Disease; 'No One's Listening' Report. HCC continues to progress action plans implemented across region.
5. Sickle Cell and Thalassaemia - a priority for Manchester Foundation Trust (MFT)
 - i. HCC Clinical Leads, Network Manager and patient representative are members of the new MFT Sickle Cell & Thalassaemia Partnership Board to improve patient care and services across Greater Manchester
6. Increased online [education platform](#) and added to HCC Website
7. Increased engagement workstreams:
 - I. Proposed Patient & Public Voice Group
 - II. Increased patient engagement events
 - III. Held monthly meetings between Network Manager and Support Groups (UK Thalassaemia Society, Sickle Cell Cares Manchester, Liverpool Sickle Cell & Thalassaemia Support Group, Congenital Anaemia Network)
 - IV. Improved relations with community stakeholders across Greater Manchester

2 GOVERNANCE

The governance arrangements for this network include the establishment of HCC Board meetings, Multi-Disciplinary Team meetings (MDTs), audit programmes and QSIS data entry.

The below diagram shows the current HCC team structure:



To provide accountability to the HCC members, the roles and responsibilities have been defined as documented below:



2.1 BOARD MEETINGS:

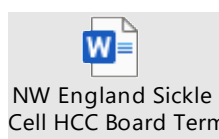
HCC Board meetings are established and embedded as business as usual, occurring quarterly, with representation from key stakeholders across the network. To allow for easy access and to maximise representation, these meetings occur virtually via Microsoft Teams.

The HCC Board is the main body for monitoring and directing compliance with clinical standards. The agenda includes quality dashboards, audit and morbidity/mortality levels. Primary input for the governance meeting is provided by the HCC Network Manager. Updates

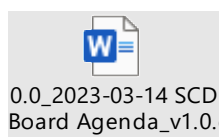
on annual action plan workstreams, policy reviews and audits are monitored and approved through the Board.

The members of the HCC Board comprise of the HCC Clinical Lead, HCC Deputy Clinical Lead, HCC Nurse Educators, HCC TCD Leads, HCC Network Manager, HCC Data Manager, SHT Clinical Leads, SHT Clinical Nurse Specialists, patient representatives, community representatives and the NHS England commissioner.

The Northwest Sickle Cell HCC Board Terms of reference are as below:



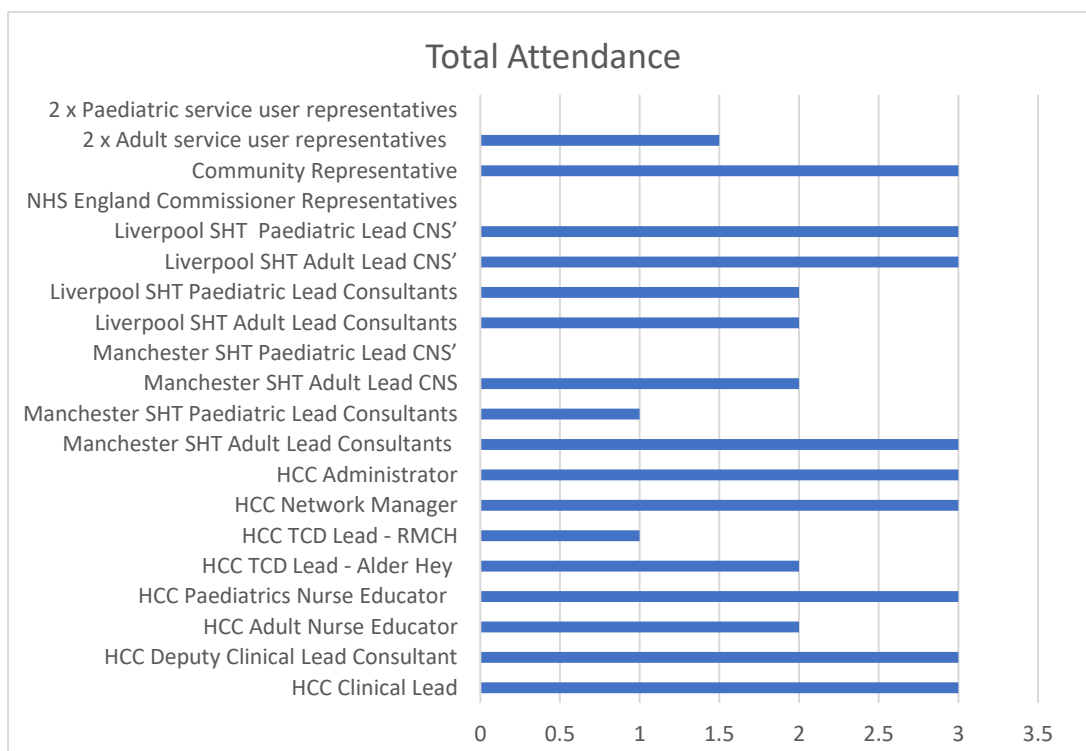
An indicative agenda is embedded below:



Board meetings have taken place on the following dates so far:

- 25.01.2022
- 20.07.2022
- 09.11.2022
- 21.03.2023

The table below shows an overall picture of engagement with HCC Board.



As a result of this participation review, Alder Hey has provided a contact for a paediatric service user representative to attend future HCC Boards. Clinical Lead Dr Grainger advised of current staffing restrictions resulting in a lack of attendance by Manchester SHT Paediatric Lead CNS.

2.2 MDT MEETINGS:

MDT meetings are established and embedded on a monthly basis. To allow for easy access and to maximise representation, these meetings occur virtually via Microsoft Teams, and alternate between a Tuesday and a Wednesday morning to allow all SHTs the opportunity to attend.

Where SHTs feel they need clinical support for patients with complex needs, they may refer to the HCC MDTs via the referral pathway. The HCC offers additional clinical specialist support and specialist advice for the management of complex patients as part of these regional MDT.

The Sickle Cell Disease HCC MDT Terms of reference are as follows and includes the MDT referral criteria:



These MDTs have good representation from the specialist haemoglobinopathy teams including representation from consultants, clinical nurse specialists, junior doctors, radiologists and when applicable, cardiology, transplant and transfusion specialists. Following implementation of the HCC medical and nursing education strategies we have invited clinicians from local hospitals to join the regional MDTs for education purposes and a means of networking with specialist haemoglobinopathy consultants and specialists.

Neuroradiology MDTs are held quarterly, consisting of expert input from radiologists and stroke specialists. We are also looking to further develop our MDTs through the inclusion of more experts from various other specialism e.g. orthopaedics and renal specialisms.

The MDT schedule for 2022/2023

Date	Time	Notes
26/04/2022	10.00-11.00	3 Cases Referred - MFT
24/05/2022	10.00-11.00	2 Cases Referred - MFT
28/06/2022	10.00-11.00	MDT Cancelled
26/07/2022	10.00-11.00	2 Cases Referred – MFT & LTHTR
23/08/2022	10.00-11.00	2 Cases Referred – MFT & LTHTR
27/09/2022	10.00-11.00	1 Case Referred - MFT
25/10/2022	10.00-11.00	MDT Cancelled
15/11/2022	10.00-11.00	2 Cases Referred – MFT & Salford Royal
14/12/2022	10.00-11.00	4 Cases Referred- MFT & Alder Hey
24/01/2023	10.00-11.00	1 Case Referred – Alder Hey
01/03/2023	10.00-11.00	MDT Cancelled
28/03/2023	10.00-11.00	MDT Cancelled - staffing

All patients being submitted for MDT discussion are collated by the HCC Data Manager and distributed to the MDT attendees. The HCC Data Manager takes formal minutes on all patients discussed and the outcomes are circulated to the network.

Following discussion of complex cases, if required, cases are referred to the National Haemoglobinopathy Panel MDT meetings.

Morbidity and mortality is discussed at HCC MDT meetings every 3 months and cases are noted at HCC Board meetings. This is a standing item on the Board agenda with cases being discussed as and when they are highlighted by the SHT teams.

Patients Referred/Discussed 1st April 2022 – 31st March 2023	
Subject	Amount
Referred patients	15
Mortality & Morbidity (M&M)	2
Total Patients discussed	16*

*Preston Mortality Not Discussed due to lack of engagement from LHT

SHT's who referred patients	
Referral Location	Amount
Manchester Royal Infirmary	10
Royal Manchester Children's Hospital	1
Alder Hey Children's Hospital	3
Royal Liverpool University & Broadgreen Hospital	0
LHT	3

The HCC will conduct an audit of case mix and review of number of patients presented.

3. Audit

Board dashboard

Since June 2021, a dashboard has been used within Board meetings to allow for regular monitoring of performance against HCC key performance indicators and identify areas of development and opportunities for shared learning.



NW SCD Quality
Dashboard Novemb

Specialist Service Quality Dashboard

The HCC submits annual data to the SSQD jointly with the North of England Thalassaemia and Rare Inherited Anaemias HCC of which MFT is also the lead.



HCC SSQD Dash
Board Submission -

HCC Audit Programme

The HCC has created an audit programme that was ratified in the November 2022 Board meeting with the aim of monitoring performance against key performance indicators and identifying areas of development and opportunities for shared learning.

The audit programme is as below:



0. 22-23 NW SCD
HCC Audit Program

4. Pathway development programme

The HCC aims to improve equity of care across the region through understanding current arrangements and comparing access to care across the region.

The following pathway development programme details the pathways which have been reviewed. Since creating the programme, a working group has been established and awaits confirmation of NW Commissioning Body post before proceeding.



NW SCD Pathway
Development Progra

LHT Mapping

Each specialist hospital in the region is linked to smaller local hospitals in their surrounding area, offering advice to the local teams. Importantly, shared care of patients occurs between specialist and local hospitals with the specialist hospitals completing the mandated annual reviews for all patients in their catchment area. The HCC have documented which local

hospitals link to each specialist hospitals. The following mapping was signed off in October 2022



List of LHTs & DGH
Aligned to SHT.ods

Trans-Cranial Dopplers

Alder Hey Children's Hospital Site:

- Two trained practitioners (Julie Smith and Kate Taylor-Robinson)
- Number of scans completed: 69
- Number of abnormal scans: 1
- Number of Normal scans: 66
- Number of Conditional scans: 1
- Number of Non-diagnostics (partial data obtained, no abnormal measurements):1

Manchester Royal Children's Hospital Site:

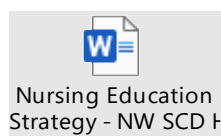
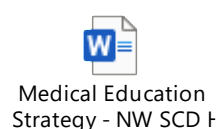
- Two trained practitioners Vivian Tang and Rob Hawkes
- Number of scans completed : 227
- Number of abnormal scans: 2 (0.88%)
 - VT =1 (MR showed recent stroke and MRA significant stenosis)
 - RH = 1 (MR showed abnormal perfusion and MRA significant stenosis. NV MDT suggested repeat MR in 6 months)
 - Interestingly, both of the above patients had normal TCD 1 year before!
- Number of Normal scans: 206 (90%)
- Number of Conditional scans: 10 (4.4%)
 - These 10 conditional TCD scans were in 7 patients.
 - Their repeat TCDs show: 3 normal/ 3 conditional (MR – 1 normal – 2 awaiting MR)/ 1 abnormal (MR- abnormal)
- Number of Non-diagnostics (partial data obtained, no abnormal measurements): 9 (4%)
 - 3 patients un-cooperative due to young age
 - 6 patients skull attenuation and poor acoustic window

5. EDUCATION AND TRAINING

Education and training is a key aspect of improving the care received by and experiences of people with a haemoglobinopathy. Due to the historic underdevelopment of haemoglobinopathy services, there is often a lack of knowledge around understanding and treatment of the disease. Therefore, a key aim of the HCC is to provide teaching sessions in the most accessible format. In 2021, the HCC laid the groundwork for understanding the needs of, mainly clinical staff in, the region and developed plans for how the HCC would provide appropriate education in the short and long-term.

To address this need for wide-spread education, the HCC developed education strategies for the medical and nursing workforces across the region. These strategies outline the target audience for education and the strategy for how the HCC aim to deliver education to this audience.

The education strategies are as below:



Following sign-off of these strategies, the HCC has identified training needs across the region, provided resources to those who require it and held various large scale and bespoke training sessions. In addition, the HCC have begun to develop a portfolio of contacts within SHTs and the wider region to ensure the education provided reaches the intended audience.

The HCC has launched a successful “lunch hour” [education series](#) in response to educational needs across the region. The HCC has conducted 11 virtual educational sessions spanning different specialities. These education sessions are documented below:

- Rare Anaemias Teaching Session - DBA and CDA by Dr Noemi Roy – 22nd October 2021
- Monitoring and Iron Chelation Therapy by Dr Nandini Sadasivam – 24th January 2021
- Paediatric Thalassaemia Teaching Session by Sarah McDonald– 11th March 2021
- Transfusion in Inherited Anaemias by Dr Noemi Roy - 4th May 2022
- Nutrition in Sickle Cell Disease by Claudine Matthews, Dietician - 22nd August 2022

- What do you need to know: 'Caring for patients with Thalassemia and Rare Inherited Anaemia' by Dr Sadasivam, Dr Kausar, Katy Stevenson, Sarah McDonald and Thomas Blair - 12th October 2022
- Transfusion in Sickle Cell Disease by Dr Sharif - 19th October 2022
- The Kidney and Beyond - Sickle Cell Disease and Transplantation by Dr Thuraisingham, Dr Samuelson and Dr El-Damanawi - 12th December 2022
- Prenatal diagnosis: Antenatal Screening in Thalassemia patients by Della Carr, Specialist Midwife, Manchester Local Community Organisation - 18th January 2023
- Blood Transfusion, Antibodies and Hyperhaemolysis in Sickle Cell Patients, Andy Houghton, Lead Clinical Nurse – Haemoglobinopathy, Royal Liverpool University Hospital – 15th February 2023
- Endocrinopathies and Bone Disease in Thalassemia, Dr Laxmi Manohar Rao Balmuri, Endocrinology and Metabolic Consultant, Manchester Royal Infirmary – 6th March 2023

All sessions were recorded and uploaded to the [education webpage](#) on the HCC Website in line with patient confidentiality guidelines. The Network Data Manager issues certificates of attendance to individuals who provide feedback. The feedback forms provide data for the HCC to understand areas of strength, areas for improvement and a list of future educational topics.

The below HCC Nurse education programme details the training sessions that have taken place between April 2022 and March 2023 (please note the calendar includes sessions for both the SCD HCC and the thalassaemia/RIA HCC):



2022 - 2023 HCC
Education Programr

In addition, the HCC nurse educators have adapted the Royal College of Nursing competencies which will guide training and hold areas accountable and were approved at the July 2022 Board.



3.3 Sickle Cell
Adapted RCN Comp

6. ENGAGEMENT ACROSS THE NETWORK

The HCC have utilised this year to raise awareness of the HCC and increase engagement with HCC activities. Prior to this year, the HCC had solidified engagement with haemoglobinopathy specialist consultants and specialist nurses within the SHTs in the HCC region. Representatives from these teams regularly attend both the regional HCC MDTs and HCC Board meetings. In addition, the HCC has developed a close working relationship with the commissioner with monthly meetings scheduled between the commissioner and Network Manager. As a result, the HCC has strengthened engagement across the region in 2022/2023.

LHT ENGAGEMENT

- SHTs have arranged several LHT Engagement Sessions throughout the year
- LHTs have nominated a lead contact
- LHTs are invited and encouraged to attend HCC MDTs
- LHTs have been invited to all educational series
- LHTs have been offered bespoke teaching sessions to suit local need
- Increase in LHT referral / contact re clinical queries

SCD Clinical Lead and Network Manager are working with UK National Haemoglobinopathy Panel and NHS England to increase engagement with a small number of LHTs who have not engaged regardless of patient safety concerns and morbidity incidents.

PATIENT ENGAGEMENT:

- Patient & Public Voice (PPV) Group pending Trust approval (June 2023)
- We have 6 sickle cell patient representatives who are encouraged to attend HCC board
- [Zone](#) dedicated to service users and patient blogs available on HCC Website
- Close working with patient support groups e.g., Sickle Cell Care Manchester (SCCM), Caribbean and African Health Network (CAHN) and Liverpool Sickle Cell and Thalassaemia Support Group.

Engagement with other key stakeholders has also taken place. These stakeholders include community teams, midwives, psychologists, commissioners and varying levels of doctors.

Members of these groups are also held on the HCC contact database, therefore, they also receive haemoglobinopathy news and education event information. These stakeholders are invited to and take part in the various working groups set up by the HCC.

The HCC also have close connections with the North East and Yorkshire SCD HCC to further ensure patients are receiving equal care across the whole of the North of England. The network managers from each of these HCCs carry out monthly catch-up meetings to aid this.

Two other key mechanisms of engagement are the HCC Twitter account and HCC website. Both mechanisms provides a snapshot of the HCC activities, promotes education events and raises awareness of haemoglobinopathy news such as the introduction of new therapies.

7. PATIENT FEEDBACK

Understanding the viewpoint of patients on the care they receive is vital to improve the service. Standardising patient experience questionnaires, in all SHTs in the network, allows for the comparison of results, leading to identification of the main problems as well as providing an opportunity for shared learning. As a result, HCC members have agreed to use standardised patient experience surveys from Sickle Cell Society. These surveys have been digitalised and shared across the network. The surveys can also be found under [Your Voice](#) in the Patient, Parent and Carer zone on the HCC Website.



Online Patient
Survey and QR Code

In addition, the HCC has proposed to implement a Patient & Public Voice Group which is currently pending Manchester Foundation Trust Approval.



Approved Terms of
Reference- TOR- Pat

The Network Manager has also collected service user feedback from patient engagements and monthly stakeholder meetings which can be read here:



Achieving
Excellence in Patient

HCC Action Plan 2021/2022

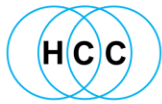


5.1 NW SCD HCC
Action Plan EC 24.01

8. PRIORITIES FOR 2023/2024



4. HCC Work Plan
2023-2024.pptx



Haemoglobinopathy Coordinating Centre
Sickle Cell: North West of England
Thalassaemia & RIA: North of England



Manchester University
NHS Foundation Trust

North of England Thalassaemia and Rare Inherited Anaemias HCC

Annual Report

2022-2023

The Royal Liverpool and
Broadgreen University Hospitals
NHS Trust

Sheffield Teaching Hospitals
NHS Foundation Trust

Alder Hey Children's
NHS Foundation Trust

Sheffield Children's
NHS Foundation Trust

The Newcastle upon Tyne Hospitals
NHS Foundation Trust

The Leeds
Teaching Hospitals
NHS Trust

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- Sheffield Children's NHS Foundation Trust
- Leeds Teaching Hospitals NHS Trust
- The Newcastle upon Tyne Hospitals NHS Foundation Trust
- North of England Thalassaemia and Rare Inherited Anaemias HCC Board Members
- North of England Specialised Commissioning Team, NHS England

Reporting Trusts	<p>Manchester University NHS Foundation Trust</p> <p>The Royal Liverpool and Broadgreen University Hospitals NHS Trust</p> <p>Alder Hey Children's NHS foundation Trust</p> <p>Sheffield Teaching Hospitals NHS Foundation Trust</p> <p>Sheffield Children's NHS Foundation Trust</p> <p>Leeds Teaching Hospitals NHS Trust</p> <p>The Newcastle upon Tyne Hospitals NHS Foundation Trust</p>
Document Prepared By	HCC Network Manager
Date	June 2023

1. INTRODUCTION

This report is to demonstrate and highlight the activity conducted by the North of England Thalassaemia and Rare Inherited Anaemias (RIA) Haemoglobinopathy Co-ordinating Centre (HCC) in line with the NHSE/I HCC service specification.

The report details HCC activity during 1st April 2022 – 31st March 2023. Our previous 2021-2022 annual report can be read here:



2021-2022 Annual
Report North Englar

The North of England Thalassaemia and RIA is a clinically led network consisting of a multi-disciplinary team, supporting both adults and children with haemoglobinopathies and the professionals/support networks caring for them. This HCC is made of 7 NHS Trusts: Manchester University NHS Foundation Trust (MFT), the Royal Liverpool and Broadgreen University Hospitals NHS Trust and Alder Hey Children's NHS Foundation Trust, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield Children's NHS Foundation Trust, Leeds Teaching Hospitals NHS Trust and The Newcastle upon Tyne Hospitals NHS Foundation Trust.

In addition to the specialist haemoglobinopathy teams in the North England, other key partnerships include local haemoglobinopathy teams, patient support groups, Manchester Sickle Cell and Thalassaemia Centre/Manchester Local Care Organisation, NHS England and other HCCs across England.

2. ACHIEVEMENTS

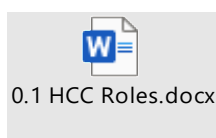
1. Great attendance at Monthly MDTs across North England
2. Launch of HCC Website and Twitter Account
 - i. <https://mft.nhs.uk/hcc/>
 - ii. @HCC_MFT
3. Responded to All-Party Parliamentary Group (APPG) Report on Sickle Cell Disease & Thalassaemia; 'No One's Listening' Report. HCC continues to progress action plans implemented across region.
4. Sickle Cell and Thalassaemia - a **priority** for Manchester Foundation Trust (MFT)
 - i. HCC Clinical Leads, Network Manager and patient representative are members of the new MFT Sickle Cell & Thalassaemia Partnership Board to improve patient care and services across Greater Manchester
5. Increased online [education platform](#) and added to HCC Website
6. Increased engagement workstreams:
 - I. Proposed Patient & Public Voice Group
 - II. Increased patient engagement events
 - III. Held monthly meetings between Network Manager and Support Groups (UK Thalassaemia Society, Sickle Cell Cares Manchester, Liverpool Sickle Cell & Thalassaemia Support Group, Congenital Anaemia Network)
 - IV. Improved relations with community stakeholders across Greater Manchester

3. GOVERNANCE

The governance arrangements for this network include the establishment of HCC Board meetings, Multi-Disciplinary Team meetings (MDTs), audit programmes and QSI data entry. The below diagram shows the current HCC team structure:

HCC Leads	HCC Clinical Lead Dr Nandini Sadasivam	HCC Deputy Clinical Lead Dr Sabiha Kausar
Nurse Educators	Adults Nurse Educator Katherine Stevenson	Paediatrics Nurse Educator Sarah McDonald
TCD Leads	Royal Manchester Children's Hospital Vivian Tang	Alder Hey Children's Hospital Kate Taylor-Robinson
Administration	HCC Network Manager Eva Clarke	HCC Data Manager Andrew Richards

To provide accountability to the HCC members, the roles and responsibilities have been defined as documented below:



3.1 BOARD MEETINGS:

HCC Board meetings are established and embedded as business as usual, occurring quarterly, with representation from key stakeholders across the network. To allow for easy access and to maximise representation, these meetings occur virtually via Microsoft Teams.

The HCC Board is the main body for monitoring and directing compliance with clinical standards. The agenda includes quality dashboards, audit and morbidity/mortality levels. Primary input for the governance meeting is provided by the HCC Network Manager. Updates

on annual action plan workstreams, policy reviews and audits are monitored and approved through the Board.

The members of the HCC Board comprise of the HCC Clinical Lead, HCC Deputy Clinical Lead, HCC Nurse Educators, HCC TCD Leads, HCC Network Manager, HCC Data Manager, SHT Clinical Leads, SHT Clinical Nurse Specialists, patient representatives, community representatives and the NHS England commissioner.

The North England Thalassaemia & RIA HCC Board Terms of reference are as below:



2022 - 2023 - North
of England Thalassa

An indicative agenda is embedded below:



0. HCC Board
Agenda 29.03.2023

Board meetings have taken place on the following dates so far:

- 05.07.2022
- 30.11.2022
- 29.03.2023

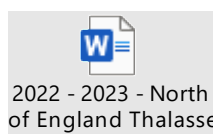
The table below shows an overall picture of engagement with HCC Board.

3.2 MDT MEETINGS:

MDT meetings are established and embedded on a monthly basis. To allow for easy access and to maximise representation, these meetings occur virtually via Microsoft Teams, and alternate between a Tuesday and a Wednesday morning to allow all SHTs the opportunity to attend.

Where SHTs feel they need clinical support for patients with complex needs, they may refer to the HCC MDTs via the referral pathway. The HCC offers additional clinical specialist support and specialist advice for the management of complex patients as part of these regional MDT.

The Sickle Cell Disease HCC MDT Terms of reference are as follows and includes the MDT referral criteria:



These MDTs have good representation from the specialist haemoglobinopathy teams including representation from consultants, clinical nurse specialists, junior doctors, radiologists and when applicable, cardiology, transplant and transfusion specialists. Following implementation of the HCC medical and nursing education strategies we have invited clinicians from local hospitals to join the regional MDTs for education purposes and a means of networking with specialist haemoglobinopathy consultants and specialists.

Neuroradiology MDTs are held quarterly, consisting of expert input from radiologists and stroke specialists. We are also looking to further develop our MDTs through the inclusion of more experts from various other specialism e.g. orthopaedics and renal specialisms.

The MDT schedule for 2022/2023

Date	Time	Notes
13/04/2022	10.00-11.00	1 Case Referred - Bradford
11/05/2022	10.00-11.00	1 Case Referred - Bradford
8/06/2022	10.00-11.00	2 Cases Referred – Newcastle
6/07/2022	10.00-11.00	3 Cases Referred – Newcastle & Sheffield
10/08/2022	10.00-11.00	1 Case Referred – MFT
14/09/2022	10.00-11.00	2 Cases Referred - Leeds
11/10/2022	10.00-11.00	1 Case Referred – Leeds
9/11/2022	10.00-11.00	Educational Focus – Study Cases discussed
14/12/2022	10.00-11.00	1 Case Referred – Leeds
10/01/2023	10.00-11.00	2 Cases Referred - Newcastle
8/02/2023	10.00-11.00	3 Cases Referred – Sheffield
8/03/2023	10.00-11.00	4 Cases Referred – Leeds

All patients being submitted for MDT discussion are collated by the HCC Data Manager and distributed to the MDT attendees. The HCC Data Manager takes formal minutes on all patients discussed and the outcomes are circulated to the network.

Following discussion of complex cases, if required, cases are referred to the National Haemoglobinopathy Panel MDT meetings.

Morbidity and mortality is discussed at HCC MDT meetings every 3 months and cases are noted at HCC Board meetings. This is a standing item on the Board agenda with cases being discussed as and when they are highlighted by the SHT teams.

Patients Referred/Discussed 1st April 2022 – 31st March 2023	
Subject	Amount
Referred patients	19
Mortality & Morbidity (M&M)	2
Total Patients discussed	21

***Preston Mortality Not Discussed due to lack of engagement from LHT**

SHT's who referred patients	
Referral Location	Amount
Manchester University NHS Foundation Trust	1
The Royal Liverpool and Broadgreen University Hospitals NHS Trust & Alder Hey Children's Hospital	0
Sheffield Teaching Hospitals NHS Foundation Trust & Sheffield Children's NHS Foundation Trust	5
Leeds Teaching Hospitals NHS Trust	10
The Newcastle upon Tyne Hospitals NHS Foundation Trust	5
LHT	0

4. BOARD DASHBOARD

Since June 2021, a dashboard has been used within Board meetings to allow for regular monitoring of performance against HCC key performance indicators and identify areas of development and opportunities for shared learning.



Dashboard - Thal &
RIA Data Board.xlsx

5. SPECIALIST SERVICE QUALITY DASHBOARD

The HCC submits annual data to the SSQD jointly with the North of England Thalassaemia and Rare Inherited Anaemias HCC of which MFT is also the lead.



HCC SSQD Dash
Board Submission -

6. HCC AUDIT PROGRAMME

The HCC has created an audit programme that was ratified in the November 2022 Board meeting with the aim of monitoring performance against key performance indicators and identifying areas of development and opportunities for shared learning.

The audit programme is as below:

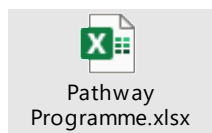


2022-2023 - HCC
North of England Ai

7. PATHWAY DEVELOPMENT PROGRAMME

The HCC aims to improve equity of care across the region through understanding current arrangements and comparing access to care across the region.

The following pathway development programme details the pathways which have been reviewed. Since creating the programme, a working group has been established and awaits confirmation of NW Commissioning Body post before proceeding.

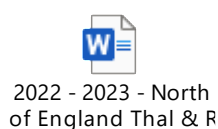
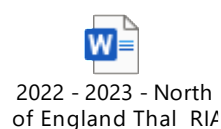


8. EDUCATION AND TRAINING

Education and training is a key aspect of improving the care received by and experiences of people with a haemoglobinopathy. Due to the historic underdevelopment of haemoglobinopathy services, there is often a lack of knowledge around understanding and treatment of the disease. Therefore, a key aim of the HCC is to provide teaching sessions in the most accessible format. In 2021, the HCC laid the groundwork for understanding the needs of, mainly clinical staff in, the region and developed plans for how the HCC would provide appropriate education in the short and long-term.

To address this need for wide-spread education, the HCC developed education strategies for the medical and nursing workforces across the region. These strategies outline the target audience for education and the strategy for how the HCC aim to deliver education to this audience.

The education strategies are as below:



Following sign-off of these strategies, the HCC has identified training needs across the region, provided resources to those who require it and held various large scale and bespoke training sessions. In addition, the HCC have begun to develop a portfolio of contacts within SHTs and the wider region to ensure the education provided reaches the intended audience.

The HCC has launched a successful “lunch hour” [education series](#) in response to educational needs across the region. The HCC has conducted 11 virtual educational sessions spanning different specialities. These education sessions are documented below:

- Rare Anaemias Teaching Session - DBA and CDA by Dr Noemi Roy – 22nd October 2021
- Monitoring and Iron Chelation Therapy by Dr Nandini Sadasivam – 24th January 2021
- Paediatric Thalassaemia Teaching Session by Sarah McDonald– 11th March 2021
- Transfusion in Inherited Anaemias by Dr Noemi Roy - 4th May 2022
- Nutrition in Sickle Cell Disease by Claudine Matthews, Dietician - 22nd August 2022
- What do you need to know: 'Caring for patients with Thalassaemia and Rare Inherited Anaemia' by Dr Sadasivam, Dr Kausar, Katy Stevenson, Sarah McDonald and Thomas Blair - 12th October 2022
- Transfusion in Sickle Cell Disease by Dr Sharif - 19th October 2022
- The Kidney and Beyond - Sickle Cell Disease and Transplantation by Dr Thuraisingham, Dr Samuelson and Dr El-Damanawi - 12th December 2022
- Prenatal diagnosis: Antenatal Screening in Thalassaemia patients by Della Carr, Specialist Midwife, Manchester Local Community Organisation - 18th January 2023
- Blood Transfusion, Antibodies and Hyperhaemolysis in Sickle Cell Patients, Andy Houghton, Lead Clinical Nurse – Haemoglobinopathy, Royal Liverpool University Hospital – 15th February 2023
- Endocrinopathies and Bone Disease in Thalassaemia, Dr Laxmi Manohar Rao Balmuri, Endocrinology and Metabolic Consultant, Manchester Royal Infirmary – 6th March 2023

All sessions were recorded and uploaded to the [education webpage](#) on the HCC Website in line with patient confidentiality guidelines. The Network Data Manager issues certificates of attendance to individuals who provide feedback. The feedback forms provide data for the HCC to understand areas of strength, areas for improvement and a list of future educational topics.

The below HCC Nurse education programme details the training sessions that have taken place between April 2022 and March 2023 (please note the calendar includes sessions for both the SCD HCC and the thalassaemia/RIA HCC):



2022 - 2023 HCC
Education Program

In addition, the HCC nurse educators have adapted the Royal College of Nursing competencies which will guide training and hold areas accountable and were approved at the July 2022 Board.



2022 - 2023
Adapted RCN Comp

9. ENGAGEMENT ACROSS THE NETWORK

The HCC have utilised this year to raise awareness of the HCC and increase engagement with HCC activities. Prior to this year, the HCC had solidified engagement with haemoglobinopathy specialist consultants and specialist nurses within the SHTs in the HCC region. Representatives from these teams regularly attend both the regional HCC MDTs and HCC Board meetings. In addition, the HCC has developed a close working relationship with the commissioner with monthly meetings scheduled between the commissioner and Network Manager. As a result, the HCC has strengthened engagement across the region in 2022/2023.

10. LHT ENGAGEMENT

- SHTs have arranged several LHT Engagement Sessions throughout the year
- LHTs have nominated a lead contact
- LHTs are invited and encouraged to attend HCC MDTs
- LHTs have been invited to all educational series
- LHTs have been offered bespoke teaching sessions to suit local need
- Increase in LHT referral / contact re clinical queries

SCD Clinical Lead and Network Manager are working with UK National Haemoglobinopathy Panel and NHS England to increase engagement with a small number of LHTs who have not engaged regardless of patient safety concerns and morbidity incidents.

11. PATIENT ENGAGEMENT:

- Patient & Public Voice (PPV) Group pending Trust approval (June 2023)

- We have 4 thalassaemia patient representatives who are encouraged to attend HCC board
- [Zone](#) dedicated to service users and patient blogs available on HCC Website
- Close working with patient support groups e.g., Sickle Cell Care Manchester (SCCM), Caribbean and African Health Network (CAHN) and Liverpool Sickle Cell and Thalassaemia Support Group.

Engagement with other key stakeholders has also taken place. These stakeholders include community teams, midwives, psychologists, commissioners and varying levels of doctors. Members of these groups are also held on the HCC contact database, therefore, they also receive haemoglobinopathy news and education event information. These stakeholders are invited to and take part in the various working groups set up by the HCC.

The HCC also have close connections with the North East and Yorkshire SCD HCC to further ensure patients are receiving equal care across the whole of the North of England. The network managers from each of these HCCs carry out monthly catch-up meetings to aid this.

Two other key mechanisms of engagement are the HCC Twitter account and HCC website. Both mechanisms provides a snapshot of the HCC activities, promotes education events and raises awareness of haemoglobinopathy news such as the introduction of new therapies.

12. PATIENT FEEDBACK

Understanding the viewpoint of patients on the care they receive is vital to improve the service. Standardising patient experience questionnaires, in all SHTs in the network, allows for the comparison of results, leading to identification of the main problems as well as providing an opportunity for shared learning. As a result, HCC members have agreed to use standardised patient experience surveys from UK Thalassaemia Society. These surveys have been digitalised and shared across the network. The surveys can also be found under [Your Voice](#) in the Patient, Parent and Carer zone on the HCC Website.



Online UKTS
Patient Survey Link:

In addition, the HCC has proposed to implement a Patient & Public Voice Group which is currently pending Manchester Foundation Trust Approval.



Approved Terms of
Reference- TOR- Pat

The Network Manager has also collected service user feedback from patient engagements and monthly stakeholder meetings which can be read here:



Achieving
Excellence in Patient

13. HCC ACTION PLAN 2022/2023



North England Thal
Action Tracker.xlsx

14. PRIORITIES FOR 2023/2024



4. HCC Work Plan
2023-2024.pptx