

North East & Yorkshire Haemoglobinopathy Coordinating Centre (NE & Y HCC)

Annual Report September 2025

Including Highlights from 2024/25 and 2025/26



Photo: NE & Y HCC Patient Event June 2025 at Sheffield Hallam University

NE&Y HCC Annual Report September 2025

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Executive Summary

Vision Statement:

Recognising the urgent need to rebuild trust and strengthen engagement with service users, the HCC is committed to embedding lived experience at the heart of its work. Guided by the Sickle Cell Society's standards and the APPG report "No One's Listening", we aim to tackle systemic inequities and deliver consistently high quality, culturally competent, and compassionate care across the network.

The 2025/26 reporting period marks a pivotal year for the North East & Yorkshire Haemoglobinopathy Coordinating Centre (NE & Y HCC), shaped by the publication of the updated NHS England Service Specification for Haemoglobinopathy Coordinating Centres (June 2025). This specification reaffirms the HCC's role in leading a coordinated, equitable, and outcomes-driven approach to haemoglobinopathy care across its network.

Strategic Aims

- Reducing morbidity, mortality, and health inequalities for individuals with sickle cell disorder (SCD).
- Improving access to specialist care, research, and novel therapies regardless of geography.
- Strengthening network-wide collaboration through governance, workforce development, and shared learning.

Challenges and Opportunities

- Recruitment to key roles remains ongoing, with efforts to address vacancies in clinical leadership and specialist support.
- The HCC is exploring innovative models of care, including:
- Digital innovations such as a refreshed website and educational video content to improve patient information and engagement.
- Innovative therapies, including preparing for the integration of gene editing treatments like exa-cel.
- Nutritional support videos, with plans to develop physiotherapy video resources in collaboration with clinical teams and the Sickle Cell Society.

Priorities for 2025/26

- Begin alignment with the new service specification, including delivery against nationally defined metrics and locally agreed workplans.
- Strengthen network maturity through improved IT infrastructure, governance, and stakeholder engagement.
- Enhance patient experience and outcomes through targeted interventions, benchmarking, and collaborative research.

Governance and Accountability

Introduction: Network Board and Clinical Leadership

The Network Board continues to provide strategic oversight and leadership across the haemoglobinopathy network, striving for high-quality, equitable care for individuals living with sickle cell disorder. This year has seen several key changes in leadership roles, reflecting both continuity and renewal within the network.

Clinical Leads

In March 2024, one of the founding Clinical Leads retired, marking the end of an era of dedicated service and foundational leadership. The position was swiftly filled by an experienced adult consultant haematologist who had previously been an active member of the network. This seamless transition ensured continuity of clinical leadership and preserved institutional knowledge, while bringing fresh energy and perspective to the role.

Lead Nurse

The Lead Nurse position, a pivotal role in providing nursing leadership and education across the network, remained vacant for several years. Initial delays were due to service pressures arising from the COVID-19 pandemic, followed by persistent recruitment challenges. We are pleased to confirm the appointment of an experienced Clinical Nurse Specialist from within the region, who will formally assume the role in September 2025. Their comprehensive understanding of local service delivery and strong commitment to specialist haemoglobinopathy care—particularly in SCD—will be instrumental in advancing nursing leadership and professional development across the NE&Y HCC.

Pain Lead

The Pain Lead position, which had not previously been appointed, was successfully filled this year. The role is now held by a pain specialist anaesthetist clinician from a Local Haemoglobinopathy Team (LHT) within the region, representing a significant advancement in the NE&Y HCC's commitment to enhancing multidisciplinary care and addressing complex pain management needs in haemoglobinopathy services. This appointment is particularly significant as it brings frontline experience and insight into the management of chronic pain, a critical aspect of care for many service users.

Network Manager

A substantive full-time Network Manager was appointed in June 2024, following a prolonged period since the departure of the previous full-time post-holder, in June 2021. The appointment brings renewed capacity for coordination, operational oversight, and delivery of the network's strategic objectives. The new manager will play a pivotal role in supporting the network, facilitating communication across providers, and ensuring the network's workplan is delivered effectively.

Stable Leadership Roles

While several roles have seen recent changes, two key posts have remained stable and continue to provide essential continuity and expertise. The Paediatric Lead and MDT & Data Manager have both brought stability, deep experience, and a clear understanding of the network's requirements. Their ongoing contributions have helped maintain momentum and ensure that planning and delivery remain aligned with the network's long-term goals.

Transcranial Doppler (TCD) Screening Lead Vacancy

The role of TCD screening lead remains unfilled, despite sustained efforts to recruit. This position is critical to ensuring the network maintains adequate numbers of appropriately trained practitioners and keeps accurate records of TCDs performed, including abnormal results. The Paediatric Lead has been proactive in trying to address this gap, issuing calls across the region and seeking support both nationally and within the regions Specialist Haemoglobinopathy Teams (SHT). Unfortunately, these efforts have not yet yielded a successful appointment.

The absence of a dedicated TCD lead poses significant risks to service delivery and patient safety. Without coordinated oversight, there is a risk of inconsistent screening practices, delayed identification of children at risk of stroke, and missed opportunities for timely intervention. The network remains committed to resolving this issue and will continue to invest time and effort into securing a suitable candidate. Ensuring robust TCD screening is essential to delivering safe, equitable, and effective care for children with SCD.

North East & Yorkshire HCC Patient and Public Voice (PPV) Group

Following an open recruitment process, the NE&Y HCC successfully established a regional Patient and Public Voice group, including the appointment of a Chair and Deputy Chairs.

To formalise the role, a Patient Representative Role Description and Person Specification was developed and published. The roles are unpaid and involve a two-year commitment, with monthly online meetings via Microsoft Teams.

The first meeting with the PPV leadership team took place on 24 October 2024, marking the beginning of a more structured and inclusive approach to patient engagement. The Patient Engagement Lead will lead on PPV activity, ensuring the group is supported. The HCC leadership team will look to ensure contributions are embedded into network governance.

Representatives are expected to contribute to decision-making, provide feedback on HCC documents, and collaborate constructively with Board members. They are considered full members of the Business Meeting and are supported through regular communication, and respectful engagement.

As part of a recent website refresh, the PPV group now has its own dedicated page:

 [Patient Engagement – NE&Y HCC](#)

This page introduces the group, outlines their purpose, and features a video explaining their role. It also includes an online application form for individuals affected by SCD, or their family members, in the region who wish to get involved.

This initiative reflects the HCC's commitment to patient-centred care and the belief that lived experience is essential in shaping equitable and high-quality services across the region

Business Meetings

In line with the previous service specification (170125S), which required HCCs to hold a minimum of two business meetings annually, the NE&Y HCC successfully re-established its Business Meetings following the appointment of the new team in June 2024. These meetings

have become a cornerstone of network governance, enabling strategic oversight, collaborative planning, and shared accountability.

September 2024 Meeting

The first meeting focused on:

- Reintroducing the Patient and Public Voice group.
- Reviewing service updates from SHTs and LHTs.
- Planning the June 2025 Patient Event Day.
- Discussing education, finance, website development, and promotional materials.
- Launching the ED Bypass pilot and reviewing regional innovation.

March 2025 Meeting

The second meeting built on this foundation and included:

- Comprehensive service updates from all network providers.
- A detailed presentation from NHSE Specialised Commissioning on the Delegation to ICBs, outlining governance, workforce, and financial implications.
- Staffing updates, including progress on psychology and benefits advisor roles.
- Risk register review and MDT/NHR data analysis.
- Planning for the June 2025 Patient Event Day.
- Finance update and winter pack allocations.
- Education and communications developments.
- ED Bypass project progress and patient experience data.
- Citizens Advice service overview, demonstrating impactful support for patients.

Slides Decks for the meetings available [NE & Y HCC Business Meeting 240913AR25.pptx](#) and [NEY HCC Business Meeting 250307AR25.pptx](#)

The next Business Meeting is scheduled for 23rd September 2025, and both regional NHSE and ICB Specialised Commissioning representatives have been invited. Their continued involvement reflects the importance of aligning network activities with national commissioning priorities and ensuring a smooth transition to delegated models.

Commissioning and System Oversight

The NE&Y HCC operates across two NHS England commissioners and several Integrated Care Boards (ICBs), adding a layer of complexity to governance, planning, and resource alignment. Despite efforts by the HCC leadership team to clarify which ICBs fall within the network footprint, this remains unresolved due to overlapping geographies and evolving commissioning structures. NHS England commissioners have been contacted and are due to attend the next Network Business Meeting to support resolution and alignment.

This coordination challenge is further compounded by the planned abolition of NHS England, announced in March 2025, with the organisation being brought under direct government control over a two-year transition period. While the full implications for specialised commissioning are not yet clear, early signals suggest a significant decentralisation of power to local systems, including ICBs. For HCCs, this may result in changes to funding flows, accountability structures, and strategic oversight. The Network Board will continue to monitor

developments closely and advocate for the needs of haemoglobinopathy service users, ensuring that care remains equitable, coordinated, and resilient throughout the transition.

April 2024–March 2025 Workplan Overview

Following significant changes within the HCC team—including the appointment of the Adult Clinical Lead and a substantive Network Manager—commissioners approved a gap year for the annual report to allow the network time to stabilise and embed new staff. An interim programme of work was developed and progressed by the HCC Leadership Team; however, it was not formally endorsed by external stakeholders due to the absence of key mechanisms such as regular Business Meetings and a functioning PPV structure. During this period, the focus was on consolidating the network's capacity, supported by both non-recurrent and additional recurrent funding. A portion of funding was ringfenced to equitably embed roles across the network, such as psychology and benefits advisors within SHTs, in line with agreed priorities and highlighted shortfalls in most recent Peer Reviews. The interim workplan included governance improvements, staff education initiatives, patient engagement planning, and steps to improve equality of access to specialist care. While some activities remain ongoing, the foundation laid during this period will support full implementation in 2025/26.

April 2025 – March 2026 Workplan Overview

Quarter 1 Focus: Financial Review and Strategic Planning

In the first quarter of the financial year, the HCC team concentrated on reviewing the budget and aligning resources with strategic priorities. This included clarifying the previous year's underspend, ensuring all expenditures were accounted for, and producing a comprehensive document outlining commitments for both staffing and non-pay budgets. As a result, the team now has a clear understanding of available resources and a structured financial plan for the year ahead.

Service Specification Alignment and Strategic Planning

Following the release of the new service specification, the team undertook a detailed review and translated the document into a working plan. A strategy meeting was held to evaluate the proposed metrics, discuss their relevance, and identify priorities for the current year and the next. This process is ongoing and expected to take time, as the team continues to refine and align its objectives with both national expectations and regional needs. For further detail, please refer to the [Network Work Plan \(Service Spec Metrics 02.06.25\) Business Meeting.xlsx](#)

Stewardship of Resources

Optimising Communication and Collaboration Across the Network

Following a review of communication platforms, the NE&Y HCC identified that its website was not effectively serving its intended audiences. It attempted to meet the needs of both patients and NHS staff in a single space, which led to confusion and reduced usability. As a result, the HCC began exploring alternative approaches to separate patient-facing and professional-facing content.

To improve internal collaboration and streamline access to resources for NHS stakeholders, the HCC developed a dedicated **Microsoft Teams infrastructure**, which has become a central hub for network-wide communication. The **General Teams channel** includes:

- **Meeting materials:** agendas, notes, and action logs from HCC meetings.

- **Guidance documents:** protocols and service specifications from all SHTs.
- **Staff development resources:** publications, reading materials, and announcements of training events.
- **National content:** documents from the National Haemoglobinopathy Panel (NHP).
- **A YouTube tab** hosting approximately 30 videos, including past webinar training sessions and educational content.

In addition to the general channel, the HCC established specialist Teams chats to support targeted collaboration, secure and centralised file sharing:

- **A Data Staff channel** for peer support, troubleshooting, and consistency in NHR reporting.
- **A Nursing channel** for Clinical Nurse Specialists to share best practice, coordinate supervision, and discuss patient care.

These developments have strengthened cross-site communication, supported peer learning, and enhanced the efficiency of network operations.

Refreshed NE&Y HCC Website: Targeted Digital Resource for Patients

As part of the network's commitment to improving access to information and optimising digital resources, the NE&Y HCC launched a refreshed website designed specifically for regional patients. The new site provides clear, targeted content tailored to the needs of individuals living with sickle cell disorder across the region, addressing previous concerns about mixed messaging and audience confusion.

To ensure the website meets patient expectations, the HCC worked closely with PPV representatives, who provided input on layout, content priorities, and accessibility. Their feedback directly shaped the structure and tone of the site, ensuring it reflects what patients said they needed.

A new feature includes a dedicated Research page, aligned with the service specification metric, which highlights opportunities for patient involvement in clinical trials and showcases the network's research activity.

The refreshed website is now a user-friendly, trusted source of information for patients and carers, supporting self-management, education, and engagement with the wider haemoglobinopathy community.

Improving Visibility and Inclusion Through Shared Resources

In 2024/25, the NE&Y HCC funded, provided, and distributed NHSE banners and posters to both SHTs and LHTs across the region. These materials, based on the national "Can You Tell It's Sickle Cell?" campaign (DHSC Campaign Resources), were used to raise awareness of sickle cell disease (SCD) among staff, patients, and visitors. They also supported wall branding efforts to make hospital spaces feel inclusive and representative of all haematology patients. This was particularly important in trusts where patients have previously felt that visual branding prioritised haem-oncology, a concern that may have been reflected in peer review reports. The strong uptake of these resources by both SHTs and LHTs was encouraging and reflects a shared commitment to improving visibility and belonging for people living with SCD. Positive feedback

from Patient and Public Voice (PPV) partners further reinforced the value of this initiative in helping patients feel seen and supported within hospital environments.

Investing in Patient Wellbeing

The Winter Packs initiative has been a deeply valued and well-received effort across the NE&Y HCC this year. Co-designed with Patient and Public Voice representatives, the packs were created to support patients with sickle cell disease during the colder months, when the risk of painful crises increases. Each item was selected with care to provide warmth, comfort, and promote hydration—key elements in managing sickle cell health. The packs included: an oversized hooded blanket (adult and child sizes), cuffed beanies (adult and junior), thermal socks (adult and child), Thinsulate gloves (adult and child), a branded bamboo eco cup, an infuser water bottle, a motivational hydration bottle, a lip balm stick, and a printed canvas bag to hold everything. QR codes linking to the NE&Y HCC website were included to raise awareness of further resources and support.

"The winter pack initiative feels like a hug in every pack; a heartfelt reminder that we are seen, heard, and understood. When the cold bites, it's more than uncomfortable; it can trigger painful crises for sickle-cell patients. That's why these packs are so deeply valued. Each item was chosen with real care... Unboxing this 'hug' from the North East & Yorkshire Haemoglobinopathy Coordinating Centre has been truly uplifting! A reminder that every patient is supported, cherished, and never alone."



Blessing Olasolomon, Chair of the NE&Y HCC

Expanding Access Through Digital Innovation

Following a proposal by a key stakeholder in response to patient requests, the NE&Y HCC partnered with an award-winning digital health innovator to support the shift toward digital healthcare. This collaboration enabled the network to provide specialist information and services not currently available regionally.

The NE&Y HCC partnered with Dr Claudine Matthews, Consultant Dietitian and founder of the Sickle Cell Nutrition Academy, to integrate nutrition into standard care for patients with SCD. A series of educational nutrition videos, curated by Dr Matthews, and in collaboration with the Sickle Cell Society, were made accessible via the refreshed HCC website, helping to bridge gaps in care and deliver equity of access to specialist nutrition advice across the region. They have since been shared with all HCCs nationally via the National Haemoglobinopathy Panel (NHP), supporting wider adoption and consistency in care across networks.

Physiotherapy Resources in Development

Building on this digital approach, the NE&Y HCC is currently working with the same partners to produce a series of physiotherapy video resources tailored for both adults and children living

with SCD. These videos aim to address the lack of regionally available specialist physio support and will be published on the HCC website once finalised.

Embedding Funding to Strengthen Network Services

The NE & Y HCC received additional recurrent funding from NHS England to strengthen haemoglobinopathy services across the region. In response to gaps identified during the recent peer review cycle—specifically the lack of consistent access to psychology and benefits advice across Specialist Haemoglobinopathy Teams (SHTs)—the Network agreed to split the funding to support these two critical areas. To ensure equity, the funding was distributed equally across all SHTs, with a further split between adult and paediatric services. This approach reflects the Network's commitment to Stewardship of Resources and its strategic aims of reducing health inequalities and improving access to specialist care regardless of geography. Implementation has been phased across sites, with just over half having successfully embedded the funding into their service models, and others progressing steadily. Once fully in place, this investment will enhance service resilience and consistency, ensuring patients across the region benefit from more holistic, equitable care.

Workforce Planning and Development

Peer reviews were conducted across all NE&Y HCC sites as part of the national quality assurance programme, offering a valuable opportunity to assess service delivery, identify areas for improvement, and share best practice. The reviews took place on the following dates: Sheffield Teaching Hospitals on 17 October 2023, Sheffield Children's Hospital on 10 November 2023, Leeds Teaching Hospitals on 15 December 2023, and Newcastle upon Tyne Hospitals on 17 January 2024. The below section provides a summary of the findings.

1. Consultant Staffing

- All SHTs had reported insufficient consultant Programmed Activities (PAs) to meet growing caseloads.
- Succession planning had been a concern, particularly where consultants had retired or were nearing retirement.
- A Consultant from Sheffield Teaching Hospitals NHS Foundation Trust (STH), the NE&Y HCC host SHT, have provided specialist in-reach support to Bradford—an area within the region where concerns around patient safety and quality of care had previously been most pronounced. Prior to this arrangement, no specialist haemoglobinopathy input was available at the Trust. The implementation of this cross-site support model has not only helped to address significant clinical gaps but also stands out as a key achievement in the network's efforts to improve equity of access and standards of care across the region.

2. Clinical Nurse Specialist (CNS) Staffing

- CNS teams had been understaffed, with limited or no cover for absence.
- CNSs had often juggled multiple roles across inpatient, outpatient, and community settings.
- Leadership time for senior CNSs had not always been protected or formally recognised.

3. Psychology Provision

- Most SHTs had lacked dedicated psychology support, with long waits or vacant posts.

4. Data Management

- A lack of dedicated data support had been a consistent issue.
- Clinical staff had often managed data tasks, which had impacted clinical time and service efficiency.
- Some temporary support in place (e.g. SCH), but long-term solutions still needed.

5. Community Services

- No formal commissioning of community haemoglobinopathy services had existed across the region.
- CNSs had provided informal outreach, but this had not been sustainable or equitable.

6. Advanced and Innovative Roles

- Pharmacist-led prescribing and nurse prescribers had been introduced in some SHTs (e.g. Leeds, SCH).
- Physician Associates and Advanced Clinical Practitioners (ACPs) had been trialled (e.g. STH), but had required clearer funding and role definition.
- Midwifery leadership and Advanced Nurse Practitioner (ANP) roles had been emerging but faced recruitment and funding barriers.

7. Training and Development

- Emergency care training had been a major gap, with low audit compliance and no formal competence frameworks.
- CNSs had needed protected time for development and training.
- Training priorities included:
 - Pain management
 - Medical and nursing staff working in the Emergency Departments and admission units should have competences in urgent care of people with haemoglobin disorders.
 - Providing training and learning for consultants covering the out of hours rota

August 2025 Peer Review Update

In August 2025, each site within the NE&Y HCC was invited to provide an update on progress made in response to the recommendations from their respective peer reviews. These updates offer insight into the actions taken to address key findings and highlight the challenges that persist across the network.

[Full details appendix - HCC Workforce Summary from Peer Reviews .xlsx](#)

Leeds Teaching Hospitals NHS Trust

The adult lead consultant continues with 3.5 Programmed Activities (PAs), which remains insufficient for the caseload and does not include dedicated haemoglobinopathy CPD time. A new consultant joined in April 2025 with 0.5 PAs (4 hours every second week) to run a red cell clinic and manage associated administration, equating to two clinics per month. An additional paediatric consultant was recruited in October 2024. The consultant commenced maternity

leave in February 2025 and was backfilled with a locum. The substantive post includes 3.125 Direct Clinical Care (DCC) Programmed Activities (PAs) allocated to haemoglobinopathy services.

CNS Staffing

The adult CNS team includes:

- A Band 7 team leader reducing to 0.5 WTE from 15 September 2025 to take up the HCC Lead Nurse role.
- A Band 6 substantive post.
- A Band 6 on an 18-month contract funded by the ED bypass pilot project.

Paediatric CNS staffing remains at 1.5 WTE shared across three nurses, with a business case for additional resources in early development.

Psychology Provision

Adults have access to 0.6 WTE psychology support. Additional provision was provided for a limited time using the NE&Y HCC funding but postholder left, recruitment to fill in progress. Paediatrics are recruiting a Family Support Worker post commenced August 2025 and interviews for a psychology assistant were held in August 2025.

Community Services

Community nursing is not formally commissioned. Adult services lost a Band 5 staff member (0.7 WTE) in May 2024, with no replacement. Paediatric services remain unchanged and are included in the business case.

Data Management

In adult services, the Data Manager works at 0.4 WTE, supported by 0.33 WTE administrative time. There has been no change in support since the previous postholder, with the current Data Manager in post since January 2021, despite a significant surge in patient numbers.

In paediatrics, there is 0.25 WTE data management support. The Data Manager handles all NHR updates and submissions, and supports the pain audit, newborn portal, and other data-related queries. A new secretary is providing some additional administrative support. Role development is underway and showing promise in reducing the administrative burden on the CNS team.

Rising Patient Numbers

Adult sickle cell caseload increased from 204 in December 2024 to 248 by July 2025 and overall there was a 66% rise in patient numbers since 2019. Paediatric numbers rose by 33% between 2020 and 2024, from 144 to 199, excluding Bradford.

Advanced Roles and Innovations

- The adult CNS is a nurse prescriber and leads a weekly hydroxycarbamide clinic, further developments planned.

Newcastle upon Tyne Hospitals NHS Foundation Trust

The paediatric consultant post, which had been vacant since January 2025, is now set to be filled with a newly appointed consultant starting in September 2025. While the exact number of programmed activities (PAs) allocated for haemoglobinopathy work is still under review, this

appointment marks an important step in stabilising paediatric medical leadership. Additionally, a new Band 6 Clinical Nurse Specialist (0.8 WTE) joined the paediatric service in June 2025 but has since commenced adoption leave; recruitment is currently underway to provide cover during her absence. Both adult and paediatric CNS teams remain single-handed, each operating at 0.8 WTE, which continues to present challenges in sustaining service resilience and continuity. Psychology provision is being strengthened through NE&Y HCC funding, with a Clinical Psychologist starting in September 2025.

Data support is limited across Newcastle with clinical staff managing data tasks.

James Cook University Hospital (JCUH), formally designated as a LHT but is effectively functioning as an SHT, providing comprehensive care and regional coordination. It was included in the peer review and continues to seek formal SHT designation, progress updates are pending.

Haemoglobinopathy care is delivered by a single consultant and Clinical Nurse Specialist (CNS), managing nearly 100 sickle cell patients across adult and paediatric services. The recent Optia MedTech Funding Mandate has strengthened service resilience, enabling NHSBT to deliver red cell exchange (RBCX) with out-of-hours provision aligned to national standards. Paediatric consultant input is available during clinics, but PA allocation remains unconfirmed.

Workforce capacity is limited, with a single CNS in post. Recruitment is underway for a 1.0 WTE CNS role, split between adult and paediatric care. Operational challenges include high DNA rates, which the team aims to reduce through improved engagement and a new administrative post

Sheffield Children's NHS Foundation Trust (Paediatric Services)

The haemoglobinopathy service continues to adapt to increasing patient numbers and evolving needs. Psychology provision has improved significantly, with 0.6 WTE dedicated haemoglobinopathy psychology now in place across two staff members, including access to neurocognitive assessments as required. A Citizen Advice Service has also been available since November 2024. However, progress in supporting the Clinical Nurse Specialist (CNS) team has been limited. CNS staffing remains at 2.5 WTE across three staff, covering inpatient, community, newborn screening results and social support roles, increasing to 2.6 WTE from September. The CNS are also covering the rest of non-malignant haematology including haemostasis and general haematology. A business case is being developed to employ a Healthcare Assistant (HCA), who would support the CNS team by undertaking bloods and deliver medication in the community. In the meantime, local community services are used for bloods when feasible, although no dedicated funding is currently available from the Trust.

Data management continues to rely on temporary support, with plans to make the role substantive pending the return of a staff member currently on maternity leave. The department includes two Advanced Nurse Practitioners (ANPs), with a third nurse currently in training. While not directly embedded within the haemoglobinopathy team, they provide ward support for patients. Consultant capacity has increased to approximately 1.2 WTE for clinical work, covering red cell, general haematology, and laboratory services. The Paediatric Lead also has time allocated for HCC duties and Head of Department responsibilities within their job plan. Education and training efforts are ongoing, with teaching provided to Emergency Department staff, although a formal competency framework is not yet in place. School education initiatives and QR code resources are active. Audit and training capacity remains constrained due to CNS

workload, but the proposed HCA role is expected to alleviate this and enable progress in these areas.

Sheffield Teaching Hospitals NHS Foundation Trust (Adult Services)

The appointment of a new consultant has increased the team's total allocation to 6.5 PAs. In addition, one consultant provides 3 PAs of support to a neighbouring Trust, separate from the Sheffield team's allocation. Recruitment challenges remain, particularly following an unsuccessful attempt to appoint to the haemoglobinopathy-specific role, which has further constrained the team's PA capacity.

The CNS team comprises 2.6 WTE across Band 6 and Band 7 staff, with one CNS undertaking a master's degree and another contributing part-time via the ED bypass pilot. Psychology provision will increase, with the post filled by September 2025. Benefits advisor input is established and ongoing funding for this service provided by the HCC. Community care is not commissioned, and allied health access is limited.

A portion of SHT Data management is provided locally, while tasks such as NHR submissions, annual review data, and new registrations are completed by the HCC data role—an arrangement that helps maintain expertise to support other regional data managers.

Foundations for Future Workforce and Service Development

The Network has identified the need for a comprehensive Training Needs Analysis. This will be a key priority for the newly appointed permanent part-time Lead Nurse, who joins the Network in September 2025. They will lead the development of a network-wide training programme, aligned with the updated service specification. While delivery will be supported by partner organisations and local teams, the Lead Nurse will play a central role in shaping both the content and structure of the programme.

Although broader support for innovative roles and recruitment strategies is scheduled for 2025/26, the Network has already begun exploring digital health innovations. These include a refreshed website—now live—and a suite of patient-facing videos, several of which are complete, with more in development. These digital tools will form a core component of the Network's strategic approach to workforce and service development in 2025/26.

Staff Education Initiatives

In November 2024, NE&Y HCC hosted a successful online Education Day, featuring sessions led by clinicians, psychologists, data managers, and Patient and Public Voice (PPV) representatives. The programme covered key topics such as pain management, hydroxycarbamide use, HbSC care, and patient experiences, and was well received across the Network.

Strengthening Regional Collaboration

Lunchtime Webinars: Specialist Training

In 2024/25, NE&Y HCC collaborated with NW HCC to deliver two lunchtime webinars as part of a joint education initiative aimed at enhancing staff knowledge and promoting cross-regional collaboration:

- Dr Claudine Matthews, Consultant Dietitian, on integrating nutrition into standard care for sickle cell disease.

- Sobia Khan, Genetic Counsellor (Bradford), on antenatal screening, psychosocial support, and community education.

Although the series is currently paused due to the absence of a Network Manager in NW HCC, it remains a promising model for ongoing professional development and consistency in care across haemoglobinopathy networks.

Gene Therapy Access

A groundbreaking gene-editing therapy for sickle cell disorder—exa-cel (commercially known as *Casgevy®*)—is now available at specialist centres in Manchester, serving the North of England. In response, the NW and NE&Y Haemoglobinopathy Coordinating Centres (HCCs) have agreed to implement a shared multidisciplinary team (MDT) approach.

This joint MDT model enables broader clinical input and peer support across both networks, enhancing decision-making around patient eligibility and case selection. While NW HCC leads on implementation, MDT coordinators from both regions collaborate closely, including on administrative functions such as secretarial support, ensuring a streamlined and cohesive process.

Quality, Safety, Experience & Outcomes

North-East & Yorkshire HCC Patient Event – June 2025

[Full report: North-East & Yorkshire HCC Patient Event June 2025](#)

Held at Sheffield Hallam University to coincide with World Sickle Cell Day, the NE&Y HCC Patient Event brought together patients, families, and professionals for a full day of education, empowerment, and community-building. With tailored sessions for adults, young people, and children, the event featured expert talks, interactive workshops, and support stalls.

Despite challenges including a heatwave and an unexpected fire evacuation, feedback was overwhelmingly positive.

Attendees praised the inclusive atmosphere and the opportunity to connect with others:
“The best thing about the event was knowing much more about nutrition and how it can improve my life as a warrior, also the deeper enlightenment of pregnancy in women living with sickle cell. I went home packed with new knowledge.”

“I really enjoyed meeting other members of the SCD community. It can often be isolating, especially with appointments, so it was nice just speaking with others about how they're finding daily life with SCD in general.”

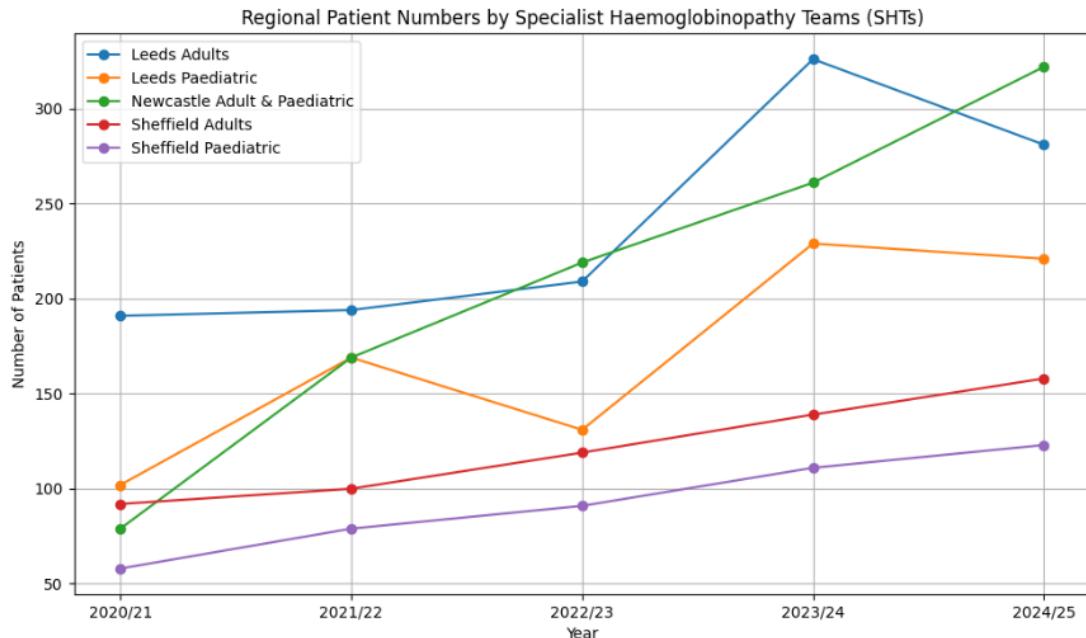
1. Regional Patient Numbers (2020–2025)

[Full report: Data and information vi](#)

This section provides an overview of key activity metrics across the NE&Y HCC network. It includes year-on-year trends in regional patient numbers by SHTs, ethnicity distribution of the patient population, and Multi-Disciplinary Team (MDT) referral activity split by adult and paediatric services. These data, drawn from past Annual Reports, local and HCC data managers,

and the National Haemoglobinopathy Registry (NHR), offer valuable insights into service demand, demographic patterns, and referral behaviours across the region.

- Total patients across NE&Y HCC increased from 522 (2020/21) to 1105 (2024/25).
- Largest growth observed in Newcastle and Sheffield teams.
- Data sourced from past Annual Reports and the National Haemoglobinopathy Registry (NHR).



2. Patient Demographics (Protected Characteristics (PCs))

- Sex: 52% Female, 48% Male.
- Age: Majority (55%) aged 18–59; 36% are children (0–14).
- Ethnicity: 81% Black/African/Caribbean/Black British; 14% Other Ethnic Groups.
- Note: Regional disaggregation by PCs is under review due to data inconsistencies.

3. Red Cell Transfusions

- 83 patients on regular red cell exchanges transfusions (RCE) and 10 patients on regular simple top-ups transfusion programmes were recorded across the HCC.
- Highest RCE activity in Leeds Adults (28) (Newcastle (31) joint figures for adult and paediatric).

4. MDT Attendance (2024/25)

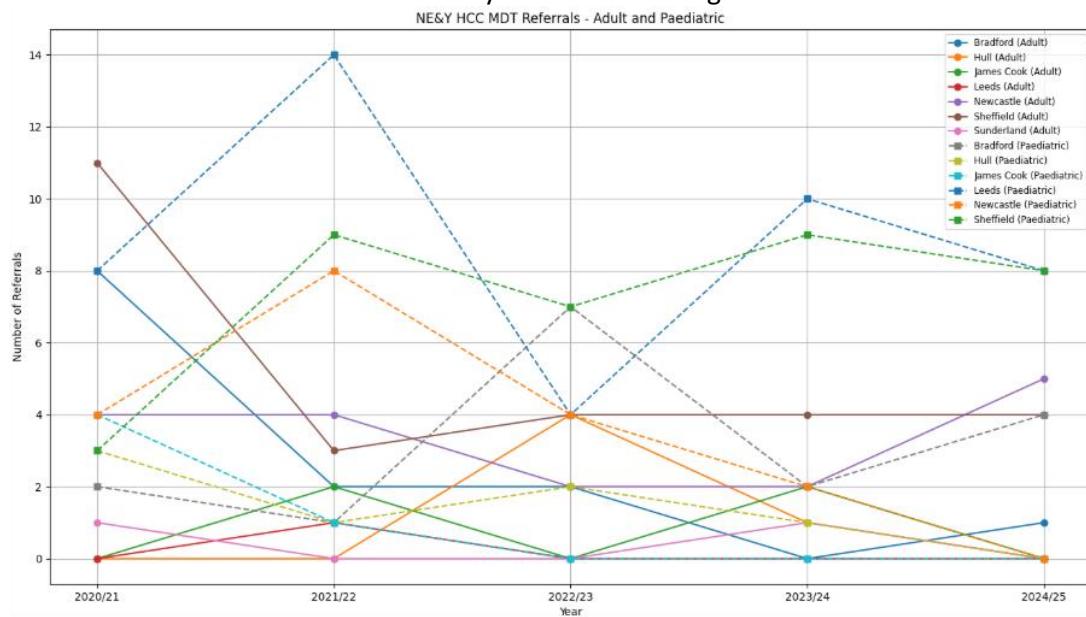
- SHTs: 66 possible attendances; 51 with at least one representative.
- LHTs: 198 possible attendances; 27 with at least one representative.
- Consistent engagement from Bradford, Sheffield, and Leeds teams.
- Due to differing working patterns among part-time consultants across the network — notably between Sheffield Children's Hospital and Newcastle — some MDTs were scheduled on days that did not align with availability for all team members. This has particularly impacted attendance from the Newcastle team, which has been the lowest across the network. In response, MDT days were temporarily adjusted to improve

accessibility; however, this was only feasible for a limited period. The HCC will consider more sustainable scheduling solutions for 2026 to better accommodate the working patterns of all teams

- Attendance from linked Local Haemoglobinopathy Teams (LHTs) has been low, other than for Bradford. This is partly due to Sheffield pathways directing all SHT patients to be treated at Sheffield Hospitals, which reduced the need for LHT involvement. A newly introduced metric highlighted that our contact list did not include LHTs linked to both Sheffield Teaching Hospitals and Sheffield Children's Hospital. This has now been addressed, with updates made from June 2025 to encourage appropriate representation going forward.

5. MDT Referrals (2020–2025)

- Adult referrals declined from 24 (2020/21) to 10 (2024/25).
- Paediatric referrals peaked in 2021/22 (34) and declined to 20 in 2024/25.
- Leeds and Sheffield consistently contribute the highest number of referrals



Adult referrals are shown with solid lines and circles, while Paediatric referrals use dashed lines and squares for clarity.

6. Serious Adverse Events (SAEs) for 2024/5

- SAE rate: 0.45% (5 out of 1105 patients).

7. Data Quality & Reporting

- Bi-monthly Data Managers meetings support data consistency and quality.
- NHR compliance actively monitored; escalations discussed at Business Meetings.

8. Service User Experience

- June 2024 survey conducted via Picker; varied methods across SHTs.
- Inconsistent implementation prevented regional comparison.

- Biennial survey cycle adopted to reduce patient survey fatigue and improve engagement.

9. Information for Commissioners

- Twice-yearly Business Meetings provide updates and performance data.
- Service proformas used to ensure structured and transparent reporting.

10. Communication & Resources

- Refreshed website offers resources for patients, families, and carers.
- Microsoft Teams channel established for staff collaboration and resource sharing.

11. Benchmarking & PROMS/PREMS

- Comparative benchmarking discussed; regional comparison limited by survey inconsistency.
- Future improvements planned to enable analysis by PCs.

12. Registry Support

- NE&Y HCC supports timely and accurate NHR submissions.
- Administrative/data support remains a challenge due to rising patient numbers.

13. Strategic Planning

- A data and information needs analysis will be discussed at the September 2025 Business Meeting.

ASCAT Attendance Support as a Continuous Improvement Initiative

In line with our commitment to continuous professional development and improving patient outcomes, the NE & Y HCC has agreed to financially support attendance at the ASCAT Conference (Excel London, 1–4 October 2025) for two adult and two paediatric representatives from each Specialist and Local Haemoglobinopathy Team (SHT/LHT) that has participated in at least one HCC MDT in the past year. This initiative enables equitable access to high-quality education and networking opportunities, fostering shared learning across the region. Eligible teams include STH, SCH, Leeds Adults and Paediatrics, Bradford Adults and Paediatrics, Newcastle Adults and Paediatrics, Calderdale and Huddersfield, Castle Hill, Sunderland, South Tees, York, and Scarborough. The HCC is also covering travel and accommodation costs directly to reduce administrative burden and ensure smooth participation. While this support reflects our current priorities, future funding for similar activities cannot be guaranteed, underscoring the importance of maximising this opportunity to strengthen clinical practice and collaboration.

Advancing Patient-Centred Care Through Accredited Education: King's College London Course Support Aligned with Strategic Goals

The NE & Y HCC is also supporting attendance at the Haemoglobinopathies: Advancing Client-Centred Care course offered by King's College London, available at both Level 6 and Level 7. This accredited programme provides in-depth, specialist education for healthcare professionals working with individuals affected by haemoglobinopathies, with a strong emphasis on patient-centred care. Financial support is being offered to one adult and one paediatric representative from each Specialist and Local Haemoglobinopathy Team (SHT/LHT) that has participated in at least one HCC MDT in the past year, mirroring the eligibility criteria used for ASCAT 2025

attendance. This initiative ensures equitable access to advanced learning opportunities and supports the development of clinical expertise across the region. As with other educational support, future funding will be reviewed annually and is subject to available resources.

Financial Reporting

Overview

The NE&Y HCC has demonstrated strong financial governance across 2024/25 and 2025/26, aligning with NHS England's Service Specifications. The network has strategically invested in workforce, patient support, education, and digital infrastructure while managing underspend and recruitment delays.

2024/25 Financial Summary

Funding Overview

Funding Type	Amount (£k)
Recurrent Funding	407.8
Non-Recurrent Funding	165.5
Total Funding Available	573.3

Forecasted Spend (as of Dec 2024)

Category	Position Dec 2024 (£k)	Forecast to Year End (£k)	Comments
Pay	-49.8	-60.8	Lead Nurse and TCD posts vacant
Non-Pay	-153.6	-210.0	Limited delivery of Benefits Advice & Psychology Support
Total Recurrent	-203.3	-270.9	
Non-Recurrent	-36.0	-48.0	Q4 23/24 top-up carried forward
Total Forecasted	-239.3	-318.9	

Strategic Investments

During the 2024/25 financial year, the network concentrated on laying the foundations for several strategic initiatives, with resources allocated to support long-term priorities.

Progress in certain areas, however, was slower than anticipated. The recruitment of the Lead Nurse and the embedding of benefits advice and psychological support services within the regional SHTs experienced delays, resulting in a notable underspend. Following constructive engagement with the Sheffield Teaching Hospitals Finance Team, an agreement was reached to carry forward the underspend into the 2025/26 financial year. This arrangement was underpinned by the submission of detailed, costed plans and a recognition of the transitional context during the reporting period.

While several activities were planned and initiated in 2024/25, their full delivery was realised in the first quarter of 2025/26. These included the distribution of Winter Packs, the hosting of a Patient Event, the production of educational videos, and the launch of a refreshed website. This phased and responsive approach to investment ensured continuity and enabled the network to maintain momentum in achieving its strategic objectives.

An underspend of £289.2k from the 2024/25 financial year was carried forward into 2025/26 as non-recurrent funding. Combined with the recurrent allocation of £410.5k, this brought the total available budget for the current year to £699.7k, supporting the continued delivery of strategic priorities.

2025/26 Financial Summary

Funding Overview

Funding Type	Amount (£k)
Recurrent Funding	410.5
Non-Recurrent Funding	289.2
Total Funding Available	699.7
Budgeted and forecasted figures	445.3
Balance Remaining	254.4

Grouped Staff Costs

Category	Post Status	Budget (£k)	Spend (£k)
Admin & Coordination	Filled	96.5	95.0
Clinical Leads	Filled	38.9	49.6
Clinical Leads	Vacant	3.5	0.0
Nursing	Vacant (until Sept)	34.4	20.3
Benefits Advice / Psychology Support	Mixed across region. Budgeted & forecasted figures	197.2	153.9

Future Spending Plans

As part of the 2025/26 strategic investment programme, the NE&Y HCC has identified key opportunities to support workforce development and enhance clinical expertise across the network. Due to time-sensitive enrolment windows, the HCC has already committed funding to support participation in the ASCAT 2025 conference (1–4 October, ExCeL London), a leading international event focused on advances in sickle cell and thalassaemia care. In addition, funding has been allocated for staff enrolment in the Haemoglobinopathies: Advancing Client-Centred Care (Level 6 or Level 7) course at King's College London, scheduled to run from 19 February to 26 March 2026. This accredited module is designed to strengthen clinical decision-making and promote evidence-based, client-centred care aligned with national service standards.

These initiatives form part of a broader set of costed proposals totalling £254,000, developed by the HCC Leadership Team in consultation with network stakeholders, and will be subject to ongoing review and prioritisation throughout the financial year.

Conclusion

The NE&Y HCC has effectively managed its financial resources across both years, balancing underspend recovery with strategic investment. The 2025/26 budget reflects a mature phase of service delivery, with full staffing, expanded patient support, and enhanced digital and educational resources.

NE&Y HCC Annual Report – Key Highlights

Strategic Focus

- Embedding lived experience in care, guided by national standards and the “No One’s Listening” report.
- Aligning with the new NHS England service specification to improve equity, outcomes, and access.

Governance & Leadership

- New appointments: Adult Clinical Lead, Lead Nurse, Pain Lead, and Network Manager.
- PPV group launched with dedicated website and monthly meetings.
- Business Meetings re-established; next scheduled for September 2025.

Workforce & Services

- Rising patient numbers (from 522 in 2020/21 to 1105 in 2024/25).
- Persistent gaps in consultant, CNS, psychology, and data support.
- Training programme in development; digital health innovations underway.

Digital & Patient Engagement

- Reestablished PPV
- Refreshed website tailored for patients.
- Nutrition and physiotherapy video resources developed.

Financial Overview

- £699.7k total funding in 2025/26.
- Strategic investments in staffing, education, and digital tools.
- Underspend from 2024/25 carried forward to support delayed initiatives.

Quality & Outcomes

- June 2025 Patient Event praised for inclusivity and education.
- MDT attendance improving; LHT engagement being addressed.
- SAE rate low (0.45%); data quality and NHR compliance actively monitored.