North East & Yorkshire Haemoglobinopathy Coordinating Centre

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

Annual Report 2025-2026



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

North East & Yorkshire Haemoglobinopathy Coordinating Centre (NE&Y HCC) Report April 2025 to March 2026
Data, Activity and Service Performance section presents information for the full 2025/26 financial year (1 April 2025 to 31 March 2026)

Introduction
This report provides an update on activity undertaken by the NE&Y HCC between October 2025 and March 2026.

It follows publication of the HCC Annual Report in September 2025, which was produced outside the usual reporting cycle to address a gap in annual reporting following a period of significant change within the HCC leadership team.

To align future reporting with the financial year, this report provides an update on key developments, achievements and challenges from the six-month period following publication of the previous report. It highlights progress across governance, service development, education, patient and public involvement, workforce, quality improvement and regional collaboration.

Whilst the narrative sections of this report focus primarily on activity undertaken between October 2025 and March 2026, the Data, Activity and Service Performance section presents information for the full 2025/26 financial year (1 April 2025 to 31 March 2026), reflecting the reporting periods used for regional activity, National Haemoglobinopathy Registry (NHR) and performance data. This approach provides a complete picture of service activity and patient population trends across the reporting year.

From 2026/27 onwards, reporting will return to a single annual cycle aligned to the financial year, providing greater consistency with NHS planning, governance and financial reporting processes.

Governance and Accountability

Introduction: Network Board and Clinical Leadership

HCC Team
Lead Nurse
Following appointment in September 2025, the HCC Lead Nurse has provided leadership for the Network's education and patient information workstreams. During the reporting period, work commenced on the review and development of patient information resources to support people living with SCD, ensuring information remains accurate, accessible and aligned with current clinical practice. This work has been undertaken collaboratively with multidisciplinary colleagues and has included engagement with the Patient and Public Voice (PPV) group to ensure resources reflect the needs and experiences of patients and families.

The Lead Nurse has also supported workforce development across the Network through direct engagement with LHTs, including the delivery of tailored one-to-one education and support sessions. These activities have strengthened links between the HCC and LHTs, promoted the sharing of best practice, and helped support the delivery of high-quality care closer to home. In addition, foundations were established for future patient education initiatives, including the development of website content and resources informed by patient and carer feedback.

Transcranial Doppler (TCD) Programme
In previous years, the absence of a dedicated Transcranial Doppler (TCD) Lead presented a significant challenge for the network, despite sustained regional and national efforts to recruit to this critical role. The lack of coordinated oversight posed risks to maintaining a sufficiently trained workforce, ensuring consistent screening practices, and supporting timely identification of children at increased risk of stroke.

This longstanding vacancy was successfully addressed with the appointment of a dedicated TCD Lead in October 2025. Initial priorities included supporting the review of the national TCD Standards and strengthening links with local and national TCD practitioners to establish an accurate picture of service provision across the region. Work has also been undertaken to identify current TCD practitioners and leads across SHTs, supporting future quality assurance and governance activities.

During the reporting period, a key focus has been the development of a more consistent regional approach to quality assurance. This has included reviewing existing local practices, engaging with national TCD colleagues regarding future quality assurance requirements, and exploring opportunities to utilise national data resources to support benchmarking and performance monitoring. These activities will help ensure greater consistency in scan acquisition, interpretation and reporting across the region, supporting the delivery of high-quality stroke risk screening and prevention for children and young people with SCD.

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

During 2025/26, the PPV Group continued to play an integral role within the HCC, ensuring that the experiences and priorities of people living with sickle cell disorder (SCD) informed service development across the region. Through regular engagement with the HCC leadership team and participation in Business Meetings, PPV representatives contributed to discussions on patient information, education, service improvement and wider Network priorities, embedding lived experience within strategic planning and decision-making.

The year saw a positive transition in PPV leadership. Following the departure of the Chair, the Deputy Chair assumed the role, providing continuity and maintaining strong engagement with the HCC. An open recruitment process was subsequently undertaken across the wider PPV membership, resulting in the appointment of four new Deputy Chairs. This expansion of the leadership team strengthened representation across the Network and brought a broader range of perspectives to support the group's work.

The PPV also expanded its programme of activity during the year. Members played a key role in developing resources and information for children, young people and families, including the dedicated Help for Children and Young Person's with Sickle Cell Disorder area of the NE&Y HCC website. They also supported the development of lived-experience content to help ensure information was relevant, accessible and reflective of the experiences of people living with SCD.

The group contributed to school and workplace support resources, awareness initiatives, patient engagement activities and signposting information. In addition, PPV members played a key role in designing promotional posters and flyers to increase awareness of the NE&Y HCC website and encourage access to the Network's growing online resource hub.

To maintain engagement and ensure ongoing input from patients and carers, bi-monthly meetings were held with the wider PPV membership alongside dedicated leadership meetings with the Chair and Deputy Chairs. These forums provided opportunities to share updates, discuss emerging priorities, gather feedback and shape the ongoing work of the HCC.

This collaborative approach has further strengthened the partnership between the HCC and the PPV, ensuring that the patient voice remains at the heart of service development, improvement and delivery across the Network.

Business Meetings
The NE&Y HCC held two Business Meetings during the reporting period, in September 2025 and March 2026. These meetings continued to provide an important forum for network governance, bringing together representatives from SHTs, LHTs, the PPV, regional commissioners and key stakeholders to review service developments, monitor risks, and agree regional priorities.

The September 2025 meeting focused on reviewing the newly published HCC Annual Report, agreeing HCC work plan priorities, discussing regional objectives, and considering proposed investment of HCC resources to support service development, education, patient engagement and workforce initiatives. The meeting also received updates on workforce developments, service innovations, patient engagement activities, regional guideline development, health inequalities work and plans to improve education and training across the Network.

The March 2026 meeting reviewed progress against HCC objectives and received updates from all provider organisations. Discussions focused on workforce pressures, regional risks, education strategy, patient information resources, peer mentoring, and service development. The meeting also considered regional risks relating to workforce capacity, access to specialist advice, equity of provision and future service sustainability, and reviewed opportunities to utilise HCC resources to support transformational projects across the region. The PPV presented an update on its expanding programme of work, including resources for children and young people, workplace and educational support initiatives, awareness activities and website development.

Throughout the reporting period, Business Meetings provided a mechanism for oversight of HCC priorities, financial planning, performance, quality improvement and patient engagement, supporting a coordinated regional approach to improving services for people living with SCD.

Stewardship of Resources
Finance and Financial Governance
The NE&Y HCC managed a total funding allocation of £706.2k during 2025/26, comprising £417.0k recurrent funding and £289.2k brought forward from previous years. Funding was used to support HCC staffing, regional clinical leadership, patient support services, quality improvement initiatives, education and training activities, and patient engagement projects across the network. During the year, approximately £173.2k was invested in HCC staffing, £153.6k in regional benefits advice and psychology support services, and £186.8k in non-pay initiatives aligned to network priorities.

A significant achievement during the year was the development and implementation of a strengthened financial governance framework. As the scope of HCC-funded activity continued to expand, stakeholders recognised the need for clearer oversight arrangements and a more transparent approach to expenditure approval. To address this, the HCC introduced a dedicated Finance Meeting Terms of Reference and Standard Operating Procedure, establishing defined expenditure approval thresholds, formal attendance requirements, deputy arrangements, and mechanisms for decisions to be submitted electronically when representatives were unable to attend meetings. These developments provided a consistent approach to decision-making and strengthened accountability across participating organisations.

The year saw continued progress towards the implementation of several major HCC-funded investments, most notably regional psychology and welfare benefits advice services. However, the development and mobilisation of these services took longer than anticipated

and remained the principal driver of the HCC's underspend position during 2025/26. Additional underspend arose from vacancies within a small number of HCC-funded posts, several of which were successfully recruited to during the year.

By March 2026, the HCC had identified an estimated year-end underspend of £192.6k. In line with the governance arrangements established during the year, stakeholders considered a range of strategic investment opportunities to maximise the benefit of these funds for patients and services across the region. Proposals considered and approved included expansion of a regional peer mentoring programme in partnership with the Sickle Cell Society, development of a psychology support video series, and support for attendance at ASCAT 2026. These discussions demonstrated the value of the HCC's governance framework in supporting transparent, collaborative and strategically aligned decision-making regarding the use of available resources.

Psychology and Benefits Advice Investment
During 2025/26, SHTs continued implementing the additional recurrent funding allocated to expand access to psychology and benefits advice services across the region. The investment was agreed in response to gaps identified through the recent UK Forum for Haemoglobin Disorders peer review programme and reflects the Network's commitment to delivering holistic, equitable care for people living with haemoglobin disorders.

Progress has varied across providers, reflecting differences in local workforce availability, recruitment challenges and existing service infrastructure. Nevertheless, all SHTs have continued to develop services and integrate the funding within local care models.

Both Sheffield Teaching Hospitals NHS Foundation Trust (STH) and Sheffield Children's NHS Foundation Trust (SCH) commissioned specialist welfare benefits advice from Citizens Advice Sheffield to support people affected by SCD and their families. Across both organisations, Citizens Advice Sheffield provided advice on benefits entitlement, disability benefits, Universal Credit, housing, employment and debt, helping to address the wider social and financial challenges associated with living with a lifelong condition

Through this service, 67 adult patients from STH received support, with 215 issues addressed and over £78,500 in financial gains secured. In addition, 87 children and families from SCH were supported, with 282 issues addressed and over £125,500 in financial gains secured, alongside further reimbursements and practical support.

Newcastle and Leeds faced greater challenges in establishing new provision where limited pre-existing services were available. Both organisations have continued to develop their models throughout 2025/26. In Newcastle, available funding has been prioritised for psychology provision, reflecting identified service needs across the network; consequently, dedicated benefits advice provision is not currently in place. Leeds has continued to develop both psychology and benefits advice services to support patients across its haemoglobinopathy network.

The Network will continue to monitor service utilisation and outcomes as services become fully embedded across the region. As psychology and benefits advice provision matures, this investment is expected to reduce inequalities, strengthen multidisciplinary care and improve patient experience and wellbeing regardless of where care is delivered.

Education and Equity
Supporting Workforce Development

Annual Sickle Cell and Thalassaemia (ASCAT) 2025

The NE&Y HCC supported attendance at the Academy for Sickle Cell and Thalassaemia (ASCAT) Conference in October 2025, enabling 19 multidisciplinary team members from across the network to attend through funding for registration, travel and accommodation.

Feedback demonstrated the significant value of this investment, with most attendees reporting that they would not have been able to attend without HCC support due to limited study leave and training budgets within their organisations.

ASCAT provided valuable opportunities for learning, networking and professional development. Delegates particularly valued updates on emerging therapies, clinical trials and research developments, educational sessions covering a range of clinical topics, and opportunities to share experiences and learn from colleagues working in haemoglobinopathy services across the UK and internationally.

Attending as part of the NE &Y HCC cohort was highlighted as a key benefit, helping to strengthen relationships between services, enhance regional networking and improve understanding of the wider haemoglobinopathy pathway. The dedicated HCC networking session was particularly well received, providing an opportunity to discuss service developments, share good practice and build connections across the region.

Overall, attendees described ASCAT as an excellent conference that exceeded expectations, returning to their organisations with new knowledge, ideas for service improvement and renewed enthusiasm for haemoglobinopathy care.

Haemoglobinopathies: Advancing Client-Centred Care (Levels 6 & 7)
The NE&Y HCC funded nine Clinical Nurse Specialists from a mix of SHTs and LHTs to undertake the course.

Feedback highlighted the significant value of the course, with participants reporting increased knowledge of haemoglobinopathies, greater confidence in caring for people with SCD and thalassaemia, and enhanced ability to deliver person-centred care. Attendees particularly valued the multidisciplinary teaching, interactive learning, networking opportunities and the chance to learn from colleagues working across haemoglobinopathy services.

The programme also supported professional development, leadership skills and service improvement, with several participants identifying opportunities to enhance patient engagement, care pathways and local service delivery.

Feedback was overwhelmingly positive, with attendees describing the course as "informative and enjoyable", "absolutely brilliant" and "invaluable". Nearly all participants advised that they would not have been able to undertake the course without HCC funding, demonstrating the importance of continued investment in specialist workforce development across the region.

Strengthening Regional Collaboration
Gene Editing Therapy Access
During 2025/26, the North West and NE&Y HCC continued to participate in a joint Multidisciplinary Team (MDT) meeting focused on exa-cel gene therapy and stem cell transplant cases. The meeting brings together specialist clinicians from both regions to discuss patients being considered for these treatment pathways and supports a consistent approach to referral assessment and case review.

Regional Education and Knowledge Sharing
Development of Network Clinical Guidelines
The HCC Service Specification requires networks to develop and maintain agreed clinical guidelines to support the delivery of consistent, high-quality care across the region. Following peer review feedback identifying this as an area for further development within the NE&Y HCC, work commenced during 2025/26 to address this requirement.

The first guideline developed was the Management of Acute Painful Crisis and Chronic Pain in Adults with Sickle Cell Disorder, led by the HCC Clinical Lead in collaboration with the HCC Pain Lead. This work established an agreed regional approach and provided a template for future guideline development.

To support the wider programme of work, the HCC commissioned both an adult and a paediatric consultant from within the network during 2025/26 to develop a suite of regional clinical guidelines and pathways. Recognising existing clinical and professional commitments, contributors were allocated a six-month development period.

This work will continue into 2026/27. Following completion of drafting, each guideline will progress through the agreed HCC governance process, including review and sign-off by relevant network stakeholders. Once ratified, the guidelines will be published on the NE&Y HCC website to support consistent practice across all SHT and LHT within the region.

This programme of work represents an important step towards ensuring the network meets the requirements of the HCC Service Specification and strengthens standardisation of care across the region.

Webinars
During 2025/26, the joint lunchtime webinar programme previously delivered with the NW HCC was not held. The programme recommenced in 2026/27 and its outcomes will be reported in next year's Annual Report.

Local Patient Engagement Events Funding
Following the success of the regional patient event in June 2025, the NE&Y HCC allocated £4,990 to each SHT (adult and paediatric services separately) to support locally delivered patient engagement and education events. The aim was to increase participation by providing events closer to patients' homes and enabling teams to tailor activities to the communities they know best. The proposal was well received by all teams.

However, delivery proved challenging. Significant delays were encountered in transferring and utilising funds, particularly outside the host SHT, due to workforce pressures, limited capacity to organise events, difficulties progressing ideas through local approval processes, and local governance requirements. While the host SHT, STH, successfully delivered a number of events and one additional team delivered within the intended financial year, all remaining teams did not receive or utilise funding until 2026/27 despite the funding being designated for use in 2025/26.

STH, will provide a full report on its activities at the October 2026 Business Meeting. Once all teams have reported on outcomes, the HCC will review whether this model represents an effective approach to patient education and engagement. In the meantime, the HCC has committed to delivering a large regional patient event every other year, with the next planned for July 2027, recognising both the value of these events and the significant time and resource required to deliver them.

Digital Physiotherapy Resources

Building on the commitment outlined in the previous Annual Report, the NE&Y HCC successfully developed and launched a series of physiotherapy and physical activity resources for children, young people and adults living with SCD. Developed in partnership with people living with SCD, parents and carers, specialist physiotherapists and the Sickle Cell Society, the resources are available through the NE&Y Sickle Cell website, ensuring access for patients and families across the region.

The video series provides practical, age-appropriate guidance on physical activity, exercise, physical development and safe movement, helping to address variation in access to specialist physiotherapy support. Resources cover a range of topics, including exercises for specific joints and muscle groups, guidance on staying active during periods of wellness and recovery, and support for physical development from infancy through to adulthood. The website also features patient stories designed to encourage engagement with physical activity and promote confidence in managing health and wellbeing.

Maintaining a Responsive Digital Resource

The NE&Y HCC website continues to serve as an important resource for patients, families, carers and healthcare professionals across the region. During 2025/26, the website was expanded with new physiotherapy resources, educational content, patient stories, information for children and young people, and resources developed in collaboration with the Patient and Public Voice (PPV) Group.

Website analytics demonstrate increasing utilisation and engagement. Between April 2025 and March 2026, the website recorded 1,979 sessions from 603 users, representing a 161.8% increase in sessions and a 45.7% increase in users compared with the previous reporting period. Visitors remained on the website for nearly six minutes on average, and almost 65% of visits involved meaningful interaction with the content. This suggests that users were not only accessing the website but were actively engaging with the information and resources available.

The most visited pages were the homepage, Resources section, About the HCC page, Patient Information page and Patient Engagement page. Strong engagement was also seen across support services, events, research information, nutrition resources and physiotherapy content, demonstrating demand for accessible information, education and self-management resources.

The website has become an increasingly important platform for sharing information, promoting educational resources, supporting patient engagement activities and signposting individuals to specialist support. Promotional activity through the PPV Group, including posters, flyers and QR-code resources, has contributed to increased awareness and use of the website. The HCC will continue to develop the website during 2026/27 to ensure patients, families and healthcare professionals have access to high-quality, up-to-date information and support.

**Engagement rate represents the percentage of website visits where users actively interacted with website content.*

Formalising Provider Agreements

Strengthening formal provider-to-provider agreements has been a key area of focus for the HCC. Historically, some network functions and services have operated through longstanding collaborative arrangements without formal contractual documentation, creating challenges in demonstrating clear governance, accountability and financial arrangements.

During 2025/26, progress continued in formalising HCC-funded services. A provider agreement remains in place with Bradford Teaching Hospitals NHS Foundation Trust to support delivery of the HCC Pain Lead role. Work has also continued between Sheffield Teaching Hospitals NHS Foundation Trust and Sheffield Children's NHS Foundation Trust to establish a formal agreement for the delivery of HCC functions. Although substantial progress has been made, completion has required review and approval across multiple departments within both organisations.

Alongside this, work has been undertaken to develop formal agreements for the regional psychology and welfare benefits services. This reflects a wider commitment to ensuring that HCC-funded activity is supported by appropriate contractual and governance arrangements, with clear responsibilities for service delivery and financial management. These discussions remained ongoing at the end of the reporting period and will continue into 2026/27.

Specialist and Local Haemoglobinopathy Team Updates
Updates presented at HCC Business Meetings during 2025/26 demonstrated ongoing development across SHTs and LHTs within the NE&Y region. Areas of progress included workforce recruitment, pathway development, patient support initiatives, research, education and quality improvement, alongside continuing challenges associated with increasing patient numbers, workforce pressures and growing demand for specialist care. The summaries below reflect updates provided at the September 2025 and March 2026 Business Meetings and represent a snapshot of service delivery and priorities at those points in time.

Bradford Adult Service
Service Development and Quality Improvement
Bradford continued to strengthen specialist service provision during the year. A significant achievement was the introduction of dedicated retinopathy screening for adults receiving iron chelation therapy, alongside the establishment of community-based sickle cell eye screening pathways. The service also benefited from the appointment of a new consultant with a red cell interest, supporting future workforce resilience and service development

Patient Support and Community Engagement
The Bradford team continued to demonstrate strong links with community services. The long-established counselling and support service remained central to patient care, providing psychological, emotional and social support from newborn screening through adulthood. The team maintained support groups for parents, young people transitioning to adult services, and adults living with SCD and thalassaemia. Community outreach activities included work with universities and GP practices to improve awareness and early identification of newly arrived students with haemoglobin disorders.

Challenges and Priorities
Despite service improvements, challenges remain around workforce capacity and infrastructure. The service reported ongoing nursing workforce pressures and continued difficulties establishing local T2* and FerriScan imaging, meaning some patients are still required to travel outside Bradford for specialist investigations. Additional pressures arise from increasing patient numbers and the expectation to support wider geographical populations without equivalent resource growth.

Bradford Paediatric Service
Service Development
The paediatric service reported stable service delivery despite changes in patient numbers associated with transition and relocation. Workforce capacity improved through the appointment of an additional consultant and increased psychology support for transition-age

young people. The introduction of local pre-exchange blood testing pathways has reduced travel requirements for families requiring exchange transfusion support.

Patient Experience
Families responded positively to HCC-supported initiatives, including the distribution of winter wellbeing packs. Additional psychology support has enhanced provision for young people approaching transition to adult services.

Challenges and Priorities
Operational challenges remain, including local phlebotomy arrangements that can delay access to blood tests and aspects of routine care. Continued service growth will require sustained workforce investment.

Leeds Adult Service

Workforce and Service Growth
Leeds continued to expand specialist haemoglobinopathy provision despite sustained increases in patient numbers. The service successfully recruited a new Band 7 Clinical Nurse Specialist during the year and maintained nurse-led holistic clinics that support comprehensive patient care. Staff also contributed significantly to regional leadership through the appointment of the NE&Y HCC Lead Nurse.

Clinical Improvement and Innovation
The service demonstrated notable quality improvement activity, including work to reduce waiting times for transfusion-related procedures. Education, improved care planning and collaborative working resulted in measurable improvements to patient experience. The emergency department bypass programme also delivered improvements in time to analgesia for patients presenting with vaso-occlusive crises.

Challenges and Priorities
Patient numbers have continued to increase significantly, with the service reporting a substantial rise in caseload compared with previous years. Consultant and Clinical Nurse Specialist (CNS) capacity remains below recommended levels, creating pressures across outpatient services, transfusion pathways and wider service delivery. Fixed-term funding arrangements and workforce sustainability remain areas of concern.

Leeds Paediatric Service

Service Development
The Leeds paediatric team strengthened multidisciplinary provision through the appointment of a family support worker and psychology assistant. Additional consultant support was secured through locum arrangements alongside future substantive recruitment.

Holistic Care and Patient Support
New roles have enhanced psychosocial support and neurocognitive assessment capacity, particularly for children requiring specialist interventions such as transplantation. The service also engaged with regional peer mentoring discussions and wider HCC-supported initiatives.

Challenges and Priorities
Workforce resilience remains a challenge. Long-term sickness absence, temporary staffing changes and pressures within associated specialist services have affected capacity, particularly within nursing and pharmacy-led clinics. Maintaining specialist support pathways while managing workforce shortages continues to be a priority.

Newcastle Adult and Paediatric Services

Service Development

The Newcastle service achieved a number of significant workforce and service developments during the year, including the appointment of new paediatric haematology staff and expansion of psychology provision. Additional investment in specialist support has strengthened multidisciplinary care and enhanced access to services for patients and families.

Patient Engagement and Wellbeing
The team delivered successful patient and family engagement initiatives, including community events, support groups and education sessions for young people. These activities have strengthened relationships between patients, families and clinical teams while supporting self-management and transition preparation.

Challenges and Priorities
Recruitment and retention of specialist staff remain key concerns. The service has highlighted challenges surrounding red cell exchange provision, workforce capacity and the implementation of a sustainable 24/7 emergency exchange service. Demand for psychological support continues to exceed available capacity despite recent investment.

Sheffield Adult Service

Service Development and Innovation
Sheffield successfully secured NHS England funding to establish a community-based service pilot aimed at improving access to specialist haemoglobinopathy care. The service also continued to develop and refine its emergency department bypass pathway, achieving improvements in treatment access and patient flow.

Service Impact
Increased psychology provision, peer support initiatives and joint transition events with paediatric services have enhanced patient experience and multidisciplinary support. The team continues to provide leadership across several regional initiatives and educational programmes.

Challenges and Priorities
The service continues to experience increasing patient numbers without corresponding growth in medical or nursing capacity. Whilst improvements have been seen in emergency care performance, delays in out-of-hours analgesia administration remain a priority area for improvement.

Sheffield Children's Hospital

Service Development
The team reported successful recruitment of an additional consultant and continued progress against peer review standards. Multidisciplinary clinics now routinely include specialist clinical, psychology and welfare support. Benefits advice provision has been particularly well received by families, helping address wider determinants of health and wellbeing.

Patient Experience and Research
Families responded positively to HCC-funded winter wellbeing packs and wider patient support initiatives. The service also expanded its research portfolio, including participation in studies accessible to children across the region.

Challenges and Priorities
The principal challenge remains nursing capacity. Existing specialist nursing staff provide support across all non-malignant haematology services, and increasing patient numbers

continue to place pressure on available resource. Business cases have been developed to address these gaps.

South Tees Service

Service Development

A major achievement for South Tees during the year was the implementation of the NHS Blood and Transplant-supported red cell exchange programme, including access to out-of-hours provision. This represents a significant improvement in local specialist care for patients requiring exchange transfusion.

Workforce and Service Infrastructure

The service secured approval for additional staffing support, including administrative resource, and established a Band 6 developmental nursing pathway following difficulties recruiting to a Band 7 post.

Challenges and Priorities

Patient numbers have increased substantially, placing pressure on existing staffing capacity. Consultant time remains below recommended levels, and recruitment restrictions have slowed service expansion. Ensuring workforce growth keeps pace with demand remains the service's principal priority.

Getting It Right First Time (GIRFT) Reviews and Emerging Themes

During 2025/26, GIRFT reviews were undertaken at Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield Children's NHS Foundation Trust and Humber Health Partnership. Leeds Teaching Hospitals NHS Trust completed the required preparatory documentation during the year, with a review date yet to be confirmed. The reviews recognised the delivery of high-quality multidisciplinary care and identified common themes relating to workforce sustainability, transition planning, data infrastructure, psychology provision and network governance. A GIRFT review of Newcastle upon Tyne Hospitals NHS Foundation Trust was subsequently completed in July 2026; however, as this falls outside the reporting period, it is not included within this report.

The findings from the GIRFT reviews were broadly consistent with issues already identified through HCC governance processes, peer review activity and service development discussions. Common themes included workforce sustainability, increasing transition activity, the need for enhanced data infrastructure, psychology provision, community-based models of care, and strengthened shared care arrangements.

The reviews highlighted many examples of good practice across the network, including innovative acute care pathways, multidisciplinary working, structured transition programmes and collaborative approaches to shared care. Recommendations were primarily focused on ensuring workforce, infrastructure and governance arrangements continue to develop in line with increasing service demand and network responsibilities.

Overall, the GIRFT findings provide independent assurance that the HCC's existing priorities relating to governance and network coordination, shared care agreements, HCC guideline development, workforce sustainability, and improvements to data and information systems remain appropriate and aligned with the needs of services across the region.

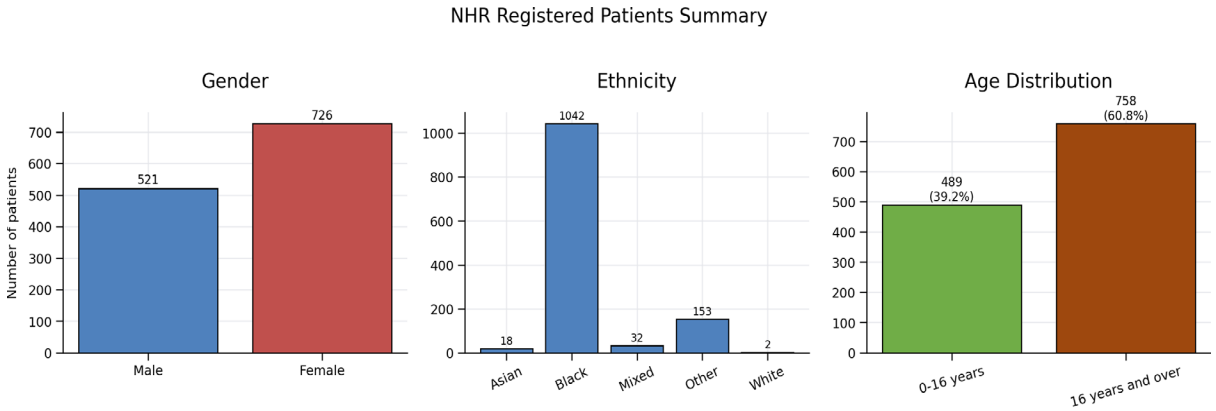
Data, Activity and Service Performance

"The prevalence of sickle cell disease in England continues to increase due to improved survival, migration patterns and population growth. SCD is now estimated to affect 12,500-

15,000 people in England and approximately 1 in 2,000 live births, making it one of the country's most common inherited conditions." (NICE, 2025)

1. Regional Patient Numbers (2020–2026)
The NE&Y HCC supported 1,247 patients with haemoglobinopathies during 2025/26, compared with 1,105 patients in 2024/25, representing an 11.4% increase in the regional patient population. This continuing growth demonstrates increasing demand for specialist haemoglobinopathy services across the region.

2. Patient Demographics (Protected Characteristics)
Females accounted for 58.2% of patients and males 41.8%. Most patients (60.8%) were aged 16 years and over, with 39.2% aged 0-16 years. The patient population remains predominantly Black/African/Caribbean/Black British (84.6%), reflecting the epidemiology of SCD within the UK.



3. Red Cell Exchange (RCE) and Simple Top-Up Transfusions
Across the HCC, a total of 105 patients were treated with regular RCE procedures and 20 with regular Simple Top-Up transfusions during 2025/26 with the highest volume of activity reported in Leeds Adult services.

Centre	RCE	Simple Top-Ups
Bradford Adult	3	0
Bradford Paediatric	2	1
Leeds Adult	36	1
Leeds Paediatric	8	10
Newcastle Adult & Paediatric	33	5
Sheffield Children's	3	1
Sheffield Teaching Hospitals	20	2
Total	**105**	**20**

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4. Multidisciplinary Team (MDT)
MDT plays a key role in supporting the management of complex sickle cell patients across the North East and Yorkshire region, bringing together specialist clinicians, clinical nurse specialists, psychologists, clinical scientists, and other healthcare professionals to ensure coordinated, patient-centred care and equitable access to specialist expertise

Attendance and Participation
During 2025/26, 12 HCC MDTs were held, with 340 cumulative attendances recorded. SHT colleagues accounted for 271 attendances and LHT colleagues for 69 attendances.

Consultants represented the largest professional group (121 attendances), followed by CNSs (89) and clinical scientists (86). Attendance peaked in October, with 40 attendees.

MDT Referrals
During 2025/26, 42 patients were discussed at the regional MDT, comprising 25 paediatric and 17 adult patients. Of those reviewed, 9 cases were escalated to the National Haemoglobinopathy Panel, including 6 adult and 3 paediatric patients. The MDT continues to provide specialist multidisciplinary review for complex cases and supports equitable access to expert advice across the region.

MDT Staff Survey
As part of the HCC's commitment to quality improvement and ensuring that the MDT continues to meet the needs of staff and support effective patient care, an MDT Staff Feedback Survey was undertaken during the reporting period. The survey sought to evaluate the effectiveness of MDT processes, communication, collaboration, and overall participant experience.

The survey received responses from 8 of the 38 staff who regularly attended MDT meetings, including consultants and CNSs. Feedback was overwhelmingly positive, with 100% of respondents reporting that the referral and case submission process was clear and that communication before, during, and after MDT meetings was effective. Team collaboration was rated highly, with most respondents selecting "Excellent", while all respondents reported being satisfied with the current MDT process and 87.5% rated it as excellent. Free-text comments highlighted the professional, supportive, and collaborative nature of the MDT, with respondents reporting that there was little need for change or improvement. These findings provide reassurance that the MDT continues to deliver a valued and effective forum for multidisciplinary discussion and specialist decision-making across the network.

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5. Serious Adverse Events (SAE)
Eleven SAEs were reported during 2025/26, equating to approximately 0.88% of the registered patient population. Seven cases were reviewed through the HCC MDT process to support shared learning, quality improvement and patient safety. During the year, the HCC reviewed and clarified expectations regarding referral of SAEs to the MDT, resulting in strengthened processes to ensure all eligible future cases are considered. Reported events included five deaths, four transfusion-related complications, one haemorrhagic stroke and one ischaemic stroke.

Comorbidities description	Total
Death	5
Delayed Haemolytic Transfusion Reaction (DHTR) - Associated with a new antibody (conventional DHTR)	1
Delayed HTR - Not thought to be associated with antibody: hyperhaemolysis	3
Haemorrhagic stroke	1
Ischaemic stroke	1
Total	11

6. Data Quality & Reporting
Bi-monthly Data Managers meetings continue to support data quality, consistency and reporting across the network. The region continues to benefit from a highly engaged and experienced group of data managers who play a critical role in maintaining the quality of local and regional haemoglobinopathy data. As a result of their commitment and expertise, the NE&Y HCC continues to achieve high levels of NHR completeness and data accuracy,

providing a strong foundation for service planning, quality improvement and performance monitoring.

NHR compliance remains a standing agenda item, with performance monitored through HCC governance arrangements. Despite strong performance, data management capacity remains variable across the region. During the reporting period, one service continued to rely on temporary data management arrangements, while another operated without dedicated data management time across both paediatric and adult services. The departure of a longstanding member of the data workforce within a large SHT also highlighted the vulnerability of some local arrangements. While teams have worked collaboratively to maintain reporting standards, sustainable investment in data management capacity remains important to support the growing patient population and ensure the region can maintain its strong record of data quality and NHR reporting.

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7. Service User Experience

Patient experience remains a key component of service development across the NE&Y HCC. The regional patient experience survey utilises the Picker survey methodology, developed in partnership with the Sickle Cell Society and used across haemoglobinopathy services for more than a decade. Recognising the importance of maintaining meaningful patient engagement while minimising survey fatigue, the HCC adopted a biennial survey cycle.

As a result, 2025/26 was a planned gap year for survey delivery.

Financial Reporting

Financial Overview

The NE&Y HCC managed a total funding allocation of £706.2k during 2025/26, comprising recurrent HCC funding and non-recurrent funding carried forward from previous years. Expenditure was aligned to the Network's agreed priorities, including HCC staffing, psychology and welfare benefits support, workforce development, patient engagement, and the development of regional infrastructure to support high-quality haemoglobinopathy care.

During the year, expenditure totalled £463.3k, with £242.9k carried forward into 2026/27. The underspend primarily reflected the phased implementation of several strategic investments, particularly psychology and welfare benefits advice services, alongside delays in recruiting to some funded posts and challenges associated with local governance processes required to establish new services and transfer funding between organisations

Financial Governance

A significant achievement during the reporting period was the strengthening of financial governance arrangements. New Terms of Reference and a Standard Operating Procedure were introduced for the HCC Finance Group, providing greater transparency and consistency in decision-making. These arrangements established clear approval processes, delegated authority limits and mechanisms to ensure that funding decisions remained aligned to agreed HCC priorities and delivered benefit across the Network.

Funding / Expenditure	£000s
Total funding available	**706**
HCC staffing	**180**
Regional psychology & benefits support	**197**
ASCAT 2025	**20**
Haemoglobinopathy Course (Level 6/7)	**33**

Local patient engagement events	**30**
Guideline development	**4**
Total expenditure	**463**
Balance transferred to 26/27	**243**

Figures are rounded to the nearest £1,000 and therefore may not sum precisely due to rounding.

The largest areas of investment during 2025/26 were regional psychology and welfare benefits provision and HCC staffing, reflecting the Network's commitment to strengthening multidisciplinary support and regional leadership. The year-end carry forward position largely reflects the phased implementation of new services, recruitment timelines and delays associated with local governance processes required to establish and mobilise new initiatives.

Funding carried forward into 2026/27 will support the continuation of agreed strategic priorities and the full implementation of projects already approved by the HCC.

Conclusion

This report demonstrates the continued progress made by the NE&Y HCC during the six months following publication of the 2025 Annual Report. Significant developments have been achieved across governance, workforce development, patient engagement, education, service improvement and regional collaboration, supported by the commitment of SHT, LHT, PPV and HCC colleagues across the Network.

Demand for haemoglobinopathy services continues to grow, reinforcing the importance of ongoing investment in workforce capacity, shared care arrangements, data quality and specialist support services. During 2026/27, the HCC will focus on delivering regional clinical guidelines, embedding psychology and welfare benefits services, strengthening network governance arrangements and continuing to improve outcomes and experiences for people living with haemoglobin disorders across the NE&Y region.