



North-East & Yorkshire HCC Patient Event June 2025



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Chief Executive of the Sickle Cell Society



2 - Dr Emma Astwood

Paediatric clinical lead, North East and Yorkshire HCC, Consultant Haematologist



3 - Dr Clare Samuelson

Adult clinical Lead North East and Yorkshire HCC, Consultant Adult Haematologist



4 - Blessing Olosolomon and Lizzy Okokwa

Chair & Deputy Chair N E & Y HCC Patient Public Voice Group, North East and Yorkshire HCC



5 - Dr Etienne Ciantar

Consultant Obstetrician, Leeds Teaching Hospital



6 - Dr Claudine Matthews

Consultant Dietitian, Sickle Cell Nutrition Academy (SCNA)



7 - Dr Mike Richards

Associate Medical Director Children's Services and Consultant Paediatric Haematologist



8 - Oluwabukola Akanni

Lead Mentor – Liverpool, Sickle Cell Society



9 - Jenni Lawrence

Children & Young Person's Haemoglobinopathy Clinical Nurse Specialist, Great North Children's, Newcastle



10 - Hekima Asilia

Thicker Than Water



11 - Tony Watson



12 - Polly Crookes

Haematology Nurse Specialist



13 - Cheryl Hall

Haematology Nurse Specialist

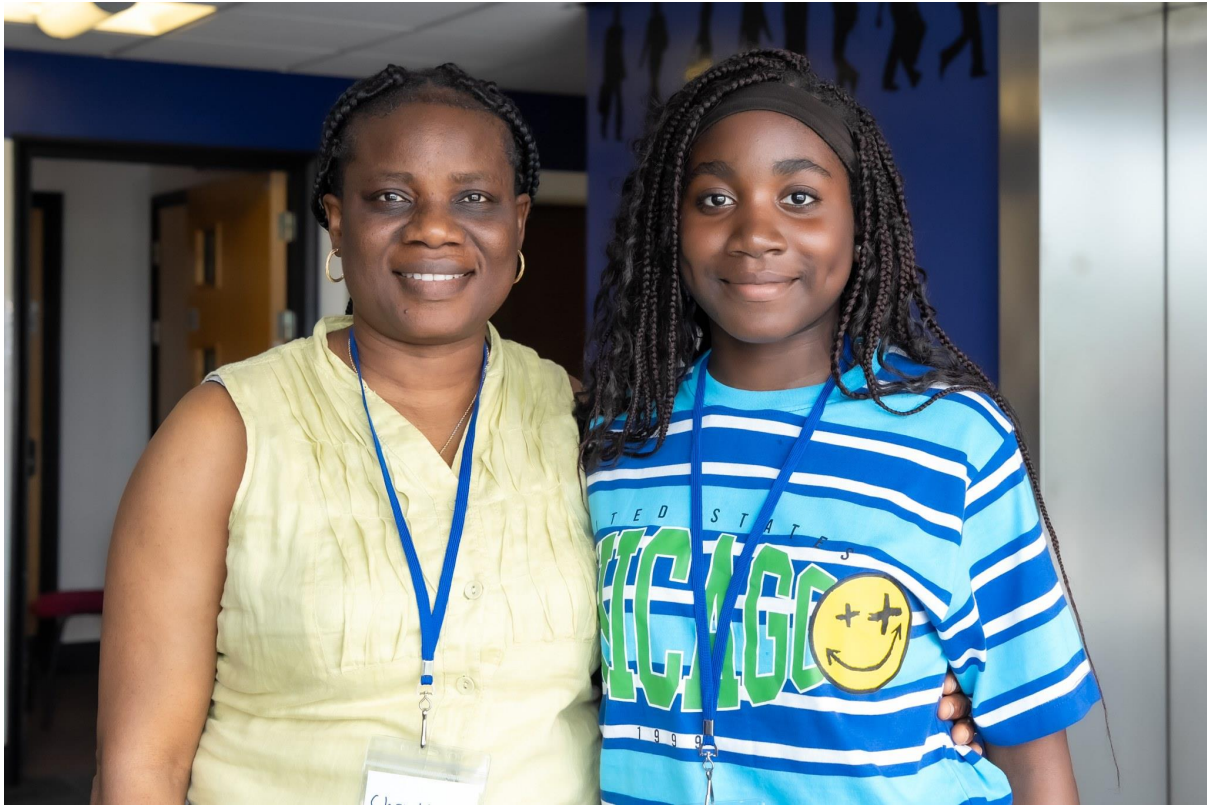
We thank all presenters for their support on the day

Executive Summary



The North East and Yorkshire Haemoglobinopathy Coordinating Centre (NE&Y HCC) Network hosted a regional **sickle cell patient event** in June 2025, bringing together patients, parents, carers, healthcare professionals and support staff for a day of learning, sharing, and collaboration. The event aimed to **empower individuals and families affected by sickle cell disorder** through education, community-building, and feedback.

Background



The regional event was held at Sheffield Hallam University (SHU), on the 21st June. SHU was chosen due to its accessibility and modern facilities. It is a good location for the [NE&Y HCC](#), with good transport links for the other Specialist Haemoglobinopathy Teams (SHTs) patients. Primarily, the date was picked to coincide with World Sickle Cell Day on the 19th June, held on a Saturday to support school age children and those who work traditional Mon-Friday, and June was hoped to be the best weather to support attendance for those with Sickle Cell Disorder (SCD).

All key stakeholders helped shape the event. Communication regarding remit of the event started in September 2024. The recently re-established Patient and Public Voice group provided guidance on topics of talks, preferred entertainers in the kids room and presented on the day. SHTs and larger Local Haemoglobinopathy Teams (LHTs) were invited to support the HCC team to engage their sickle cell patients to attend the free, full-day event. SHT and LHTs teams attended the event, supporting with different roles such as registration desk, floor walkers and presenters, making the day a NE & Y HCC network collaboration.

Transport was provided for all attendees from their SHT/LHT to SHU.

The event featured four distinct zones:

- **Conference Room:** Adults and carers attended expert-led sessions from healthcare professionals and motivational speakers, covering key medical insights and personal journeys related to SCD.
- **Young Persons Education Room (ages 8–17):** Young people engaged in tailored educational activities and interactive workshops, including sessions from paediatric specialists, promoting empowerment and peer support.
- **Kids Zone:** Children aged 8 and over, either living with SCD or children of adult patients, enjoyed supervised fun activities in a safe, inclusive space.
- **Stalls:** There were several stalls for patients to engage with during registration and breaks. Stall holders included Sickie Cell Society; Citizens Advice Sheffield; DAMU; Improving Black Health Outcomes (IBHO), Sickie Cell Nutrition Academy (SCNA), and South Yorkshire Sickie Cell Organisation (SYSCO).

Patients were welcomed to the event by [Rock Choir | The UK's original, award-winning, local, contemporary choir!](#), the UK's award-winning contemporary choir. All food and refreshments were provided on the day starting with pastries and tea/coffee on arrival, two comfort breaks, lunch and ended with food parcels at the end of the day.

The day took place in the middle of a heatwave, which coupled with coach companies sub-contracting without our knowledge, an unplanned fire evacuation all impacted on elements of the day but the overwhelming experience was positive.

Finances

The event cost £22k, a little over 50% of the annual non-pay budget recurrent funding the HCC receives. Registered numbers for the event was approximately 15% of the NE & Y HCC total numbers.

Patient Feedback Highlights



Overall Experience

- Patients expressed appreciation for the opportunity to attend the event and engage with healthcare professionals and peers.
- The atmosphere was described as welcoming and inclusive, with positive comments on the performances and activities.

Best Aspects of the Event

Key highlights mentioned by attendees included:

- Learning about new treatments for SCD
- Sessions on fertility, pregnancy, and nutrition
- Opportunities for networking and community support
- The inclusive and family-friendly atmosphere, especially appreciated by attendees with children
- The Rock Choir performance and smooth registration process

Suggestions for Improvement

While most found the event well-organised, some suggestions included:

- More interactive elements like games, quizzes, and raffles
- Hard copies of presentations for future reference
- Sessions on pain management
- Improved sound quality in some talks
- More time for informal networking

Feedback for Organisers Participants praised:

- The smooth registration and travel arrangements
- Catering that met dietary needs, including halal vegan options
- The thoughtful planning and inclusivity
- The length of the event, which was generally considered appropriate



14 - 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.

Patient feedback



15 - The whole event was informative - well done to all involved in organising it

Patient Feedback



16 - 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.

Patient feedback

NHS Staff Feedback Highlights



Positives

- Enjoyed meeting staff and nurses from across the area.
- Felt the day was well-planned and staff were kept informed.
- Children enjoyed circus, slime, and metal art activities.
- Fire alarm was well managed with no distress to children.

- Afternoon sessions were engaging, especially puberty and nutrition talks.
- Felt supported by HCC Team throughout the day.
- Overall, the day was enjoyable and impactful.
- Praised coordination of a large and complex event.

Challenges & Suggestions

- Split floors made it difficult for parents to attend adult sessions and caused confusion.
- Late arrivals impacted registration flow.
- Suggested improvements: better venue layout, creche, separate sessions for affected children and siblings.
- Activity sessions had wide age ranges; suggested smaller groups or more volunteers.
- Suggested grouping children by role (e.g., affected vs. siblings) and rotating through sessions.
- Fire alarm evacuation lacked clear roles and assembly points.
- Busy registration desk made it hard to complete details.

Conclusion



The NE & Y HCC Patient Event 2025 was a resounding success, with overwhelmingly positive feedback. Attendees appreciated the educational content, the opportunity to connect with others, and the inclusive environment. Suggestions for future events include enhancing interactivity, providing printed materials, and continuing to prioritise accessibility and community engagement.

Contact Us

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