

Response to the APPG on Sickle Cell and Thalassaemia inquiry into Sickle Cell and Thalassaemia service improvement

The British Society for Haematology (BSH) has been bringing haematology professionals together since 1960 to transform the care our members provide to patients. With over 3,000 members worldwide, BSH is the largest UK haematology organisation and the only society to cover all aspects of the specialty.

The British Society for Haematology (BSH) welcomes the opportunity to contribute to this inquiry.

This response is based on experiences of BSH members and haematology professionals working directly within haemoglobinopathy services across England, including consultant haematologists, specialist nurses and clinical leads across Leeds, London and the South East. We spoke with 8 individuals and our response reflects their experiences of delivering care for people living with sickle cell disease and thalassaemia and highlights recurring themes identified across multiple submissions.

While experiences vary between services and regions, those consulted consistently reported that national investment and improvement initiatives have driven meaningful progress in care over recent years. At the same time, they highlighted ongoing challenges relating to workforce capacity, variation in service provision and concerns about the long-term sustainability of recent improvements.

Improvements in Care

Contributors reported significant improvements in the care available to patients with sickle cell disease and thalassaemia over the last five years.

Improvements highlighted included:

- stronger haemoglobinopathy networks and greater collaboration between centres, supported by Haemoglobinopathy Coordinating Centres, specialist multidisciplinary working and national expert forums;
- expansion of specialist workforce provision;
- increased availability of educational resources for healthcare professionals and patients;
- development of community haemoglobinopathy services and patient support programmes, helping improve access to specialist care and support closer to home;

- establishment of Acute Sickle Cell Units (ASCUs) and emergency department bypass pathways, improving access to specialist assessment and reducing delays in treatment;
- improvements to exchange transfusion and apheresis services, supported by national investment in equipment, workforce development and service expansion;
- Implementation of Digital and Universal Care Plans, improving access to patient-specific information across healthcare settings;
- increased focus on haemoglobinopathy services through national improvement programmes.

They also highlighted improvements in the adoption of digital systems and nationally coordinated initiatives, including electronic patient alerts, Universal Care Plans, the National Haemoglobinopathy Panel and educational tools such as ACT NOW, which have supported more consistent care and improved communication between services.

Several respondents reported that dedicated funding through the NHS England Sickle Cell and Thalassaemia Improvement Programme had enabled developments that would otherwise not have been possible.

However, some individuals noted that improvements have not been experienced uniformly across England and that variation in access to specialist expertise and services remains a significant concern.

Impact of Acute Sickle Cell Units and Bypass Pathways

Clinicians involved in ASCUs and bypass services described these initiatives as among the most impactful developments in recent years. It was reported that these services have:

- improved patient access to specialist advice, outreach services and coordinated care;
- reduced delays in pain management;

- enabled patients to bypass overcrowded emergency departments;
- supported delivery of individualised care plans; and
- facilitated education and training for emergency department, acute care and ambulance staff.

Clinicians also reported that bypass services have enabled increased specialist nursing and Advanced Clinical Practitioner capacity, improving patient access to specialist advice, outreach support and coordinated care.

Submissions received emphasised that patients with sickle cell disease often report greater confidence in services when assessed by staff with specialist expertise and familiarity with their condition.

Several clinicians described measurable improvements in achieving NICE standards for timely analgesia following implementation of bypass pathways, with some reporting analgesia within 30 minutes in 80-100% of attendances and substantial reductions in length of stay.

Respondents also noted ongoing pressures within emergency departments, including overcrowding, delays to treatment and prolonged waits for admission. Respondents felt bypass pathways had helped mitigate these issues and provided a more appropriate environment for patients experiencing acute sickle pain.

Education and Training

There were reported improvements in education and training over recent years, particularly through haemoglobinopathy networks, specialist services and national initiatives.

Respondents highlighted increased availability of educational resources and improved opportunities for professional development. Examples highlighted by members included Haemoglobinopathy Coordinating Centre educational programmes, UK Forum for Haemoglobin Disorders resources, specialist conferences, trust-based education programmes and clinical tools designed to improve recognition and management of sickle cell disease in acute care settings.

However, some individuals noted that progress has been uneven and that training does not consistently reach all staff groups involved in caring for patients with sickle cell disease and thalassaemia, particularly within emergency departments and non-specialist settings. It was therefore emphasised by contributors the importance of continuing education initiatives across the wider health system.

Workforce Capacity

Workforce pressures were identified as a significant challenge by multiple respondents.

Clinicians highlighted:

- difficulties recruiting and retaining consultant haematologists with haemoglobinopathy expertise;
- shortages within the specialist haemoglobinopathy workforce;
- insufficient dedicated programmed activity time for haemoglobinopathy services;
- increasing patient numbers, growing complexity of care, and rising demand associated with new therapies, expanding treatment options and longer-term management needs; and
- concerns regarding long-term workforce sustainability.

Several respondents expressed concern that haemoglobinopathy services are not always afforded sufficient priority within workforce planning, despite increasing demand and the complexity of care required for patients with sickle cell disease and thalassaemia.

It was noted by some that some services continue to lack adequate consultant job-planned sessions to support both direct patient care and the supervision of resident doctors and Advanced Clinical Practitioners (ACPs).

Respondents emphasised that sustained investment in the haemoglobinopathy workforce, including training, specialist expertise, research capacity and clinical leadership, will be essential to maintain recent improvements in care and ensure services can meet future demand.

Ongoing Variation in Care

While significant progress was reported, some respondents also identified continuing variation in service provision across England.

Examples highlighted included variation in:

- access to specialist expertise;
- availability of bypass pathways and ASCUs;
- emergency care experiences;
- workforce capacity; and
- access to community haemoglobinopathy services.

Members suggested that national oversight has played an important role in reducing variation and expressed concern that improvements may not be sustained without continuing support.

Digital Care Plans

A small number of practitioners highlighted the benefits of Digital Care Plans and Universal Care Plans. Respondents reported that these plans improve access to patient-specific information, support more consistent decision-making and can be particularly valuable when patients present to services that are unfamiliar with their individual clinical history and care requirements.

It was noted in submissions that Digital Care Plans can support timely access to important information including analgesia plans, transfusion histories and treatment details, helping to avoid delays in care, support safer clinical decision-making and facilitate safe transfusion practice.

Respondents also highlighted their value in supporting communication across organisations and empowering patients to advocate for their own care when attending emergency services. There was emphasis that the ongoing value of Digital Care Plans depends on regular review and updating to ensure information remains accurate and relevant.

Sustainability of Recent Improvements

A recurrent theme across responses was concern regarding the long-term sustainability of recent improvements in haemoglobinopathy services.

Several respondents described Acute Sickle Cell Units (ASCUs), emergency department bypass pathways and community haemoglobinopathy services as highly effective models of care that have delivered tangible benefits for patients, including improved access to specialist support, more timely treatment and improved patient experience.

However, concern was expressed that funding for some of these initiatives remains uncertain. Respondents highlighted the risk that successful services and models of care could be reduced or lost if dedicated funding is not continued. Respondents consistently emphasised that many of the most successful developments in recent years, including ASCUs, community haemoglobinopathy services, Digital Care Plans and service expansion initiatives, were made possible through dedicated national investment and have yet to become fully embedded within routine funding arrangements. Several clinicians warned that uncertainty regarding future funding is already affecting service planning and creating concern about the long-term sustainability of services, despite evidence of improved patient care and experience.

Concerns were also raised regarding workforce stability. Uncertainty regarding future funding was described as affecting staff confidence, with some specialist staff reportedly considering alternative employment due to concerns about the long-term security of their posts. Respondents highlighted the risk that posts established through improvement funding may not be sustained, potentially resulting in the loss of specialist expertise, workforce capacity and service momentum that has taken several years to develop.

There was clear emphasis that long-term funding is needed not only to maintain existing services but also to ensure that successful models of care become fully embedded and sustainable over the longer term, rather than remaining dependent on short-term funding arrangements. Several respondents also highlighted the importance of continued national leadership, coordination and oversight to reduce variation in care and support the consistent implementation of improvements across the country.

Conclusion

Clinicians consistently reported that many of the improvements described in this submission were enabled through the NHS England Sickle Cell and Thalassaemia Improvement Programme. Continued investment, national leadership and workforce development will be essential to sustain progress and reduce variations in care. BSH will continue to support improvements in haemoglobinopathy care through the development of clinical guidelines, educational activities, inclusion of haemoglobinopathy topics within the BSH annual conference, support for the ASCAT conference, and the work of relevant Special Interest Groups and Task Forces.



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