

All-Party Parliamentary Group on Sickle Cell and Thalassaemia inquiry into sickle cell care – Response from RCPATH Transfusion Special Advisory Committee

Information about the RCPATH Transfusion SAC:

The Royal College of Pathologists' mission is to: advance the science and practice of pathology; further public education in the field of pathology; and, promote study, research and innovation in pathology and disseminate results. The Specialty Advisory Committee (SAC) has delegated responsibility from Council for matters, including the professional, clinical and continuing professional education functions relating to their specialty and this is the collated response on behalf of the Transfusion SAC of RCPATH. Membership of the SAC comprises of health care professionals from all 4 UK countries and from varied backgrounds: clinical, laboratory and academic. Further information can be found at this link: <https://www.rcpath.org/profession/committees/transfusion-medicine.html>

Key points to highlight:

- Transfusions are a key component in the management of patients with haemoglobinopathies including sickle cell disorder, both in acute and chronic setting. But several gaps in practices have been identified through haemovigilance reporting (that is reported adverse events of transfusion) and patient safety incidents that need to be addressed urgently to optimise care provided for these patients
- There is great variation in the care provided to patients and the following are the key principles which underpin the standards of care for sickle patients which are not always followed:
 - a need for person-centred approaches with individualised care plans
 - equity of care provided within communities and geographically across regions
 - access to timely treatment and prompt management (avoidable delays in initiating pain relief for painful crises) given the severity of pain and the possibility of serious deterioration in acute crisis
 - Evidence based management to allow the most suitable treatment to be available
 - Shared care is not always equating to sharing valuable health care information
 - collaboration and partnership between professional bodies including sharing relevant information so that appropriate management decisions can be made (for e.g. sharing information on antibodies detected)
 - Accountability and transparency
 - Sharing lessons learnt including learning from haemovigilance reporting
 - Sustainability of changes to practices through consistent and thorough education at all levels of the health care system
- The following are enablers for changes to address these gaps and are detailed further in the responses to the key questions in the brief:
 - Adequate resources including funding to optimise services provided through fair and adequate commissioning of services
 - Technology- improving inter-operability between various IT systems in different sectors of the NHS (described further under the questions)
 - Data and information- access to up to date information especially about alloimmunisation and special requirements
 - Health workforce- knowledgeable, competent, adequate workforce with good skill mix
 - Improving education and training and addressing knowledge gaps – team-based learning, interprofessional learning and knowledge of the principles driving the treatment decisions is vital
 - Patient and family education

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Responses to the specific questions in the brief:

For healthcare professionals

- **In your experience, to what extent does the care provided to sickle cell patients meet appropriate standards of care?**
 - Often a lack of awareness of the indications for transfusion and need to find out transfusion history from previous trusts – this is a major problem as hospital laboratories may not be aware of historic antibodies or need to check national records due to lack of education/awareness
 - Lack of awareness of the risk of transfusion reactions in these patients, signs of transfusion reactions often mistaken for symptoms relating to sickle crisis
 - Lack of awareness of the specific requirements for transfusion, failure to provide red cells that are phenotype matched to reduce risk of alloimmunisation prior to primary transfusion
 - Lack of awareness of specific requirements for elective transfusion of red cells during pregnancy, failure to provide CMV negative red cells leading to fetal complications
- **Where care for sickle cell patients does not meet an appropriate standard of care, what are the reasons for this?**
 - Lack of education / awareness amongst medical, laboratory and nursing teams and poor communication/lack of robust systems to prevent errors
 - Lack of robust communication process between shared care centres to ensure that procedures are in place to deliver appropriate transfusion care wherever the patient is treated
 - Lack of interoperability of IT systems between shared care centres which could be utilised to communicate patient specific requirements. Laboratory testing often performed in referral centres rather than local hospitals, there is a lack of interoperability between the IT systems, leading to delays in updating local information and manual transcription errors
 - Lack of a national IT database for transfusion history and specific requirements for this patient cohort. Variability in processes within treating hospitals for ordering transfusions, including specific requirements and alloantibody history, many using paper-based systems and majority reliant on the knowledge of the requestor. Requestors may not realise the importance of stating that the patient has SCD or Thalassaemia on the transfusion request form
 - Lack of IT systems (Electronic Patient Record and ordering systems for blood) that can provide clinical decision support to support good practice in transfusion ordering when patient with sickle or thalassaemia diagnosis requires transfusion and transmit relevant information to laboratory IT system. Laboratory haematology IT systems should be capable of providing automatic alerts to transfusion IT systems when a SCD or thalassaemia patient is identified, which may be at pregnancy booking, pre-operatively, GP screening, admission. This is not available in all laboratories, if any, across the UK currently. Transfusion laboratories are using their IT systems to support good practice, but the system is only as good as the information that is put in, there is a need for improved communication relating to transfusion requirements for these patients. SHOT reports note that even where transfusion IT systems do include decision support alerts, these are ignored or overridden because they are not appropriately configured, too easily overridden or there are too many resulting in alert fatigue. Transfusion IT suppliers should ensure that their systems support good practice for SCD and thalassaemia patients, with appropriate algorithms based on diagnosis and with appropriate alerts.
- **To what extent do you feel you and other colleagues receive sufficient training and education around sickle cell disease?**
 - Haematology specialist training is variable – often only 3-month experience in a 5-year training programme. Some areas of the country do not have many patients and therefore trainees do not get required experience.

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- Education and training are available but will be variable across the UK. It is inevitable that education and training will be at a higher level in areas where sickle cell disease and thalassaemia are more prevalent.
 - Essential information about sickle management and care needs to be incorporated into undergraduate medical school curriculum as well as nursing curriculum – this is vital to improve patient safety
 - Education and training do not translate into good practice, errors are still made by staff who have been trained and competency assessed. This is particularly true where training and education are not enacted on a regular basis, where SCD and thalassaemia patients are not treated regularly in hospitals (low prevalence areas). This is why clinical and laboratory decision support is vital in ensuring patient care, checklists can be useful to focus attention, but IT can provide a more robust process.
 - At major centres treating sickle cell disease, education must be resourced and provided to all relevant staff, so sickle cell patients are always treated comprehensively and promptly
- **What is your experience of how haematology teams and other secondary care teams work together and engage with one another? Are there any improvements that could be made to ensure better joined-up care?**
 - New NHSE network of care model has provided structure to improve and standardise care between specialist centres and provide support to local hospitals. This is work in progress.
 - **How many ‘near misses’ of a Serious Untoward Incident have you encountered in relation to sickle cell patients?**

For healthcare bodies

To what extent does your organisation believe the care provided to sickle cell patients meets appropriate standards of care?

- Aware and supportive of the changes in commission and service redesign to haemoglobinopathy services, this is a huge step forward. The system should allow for a good national network of support and hopefully leading to further improvements to patient care. Currently while much has improved there are likely still to be patches of inconsistent, inadequate, or inequitable care (access to automated red cell exchange, choice between local nonspecialised care or non-local specialised care without friend and family support)
 - Adverse events related to inappropriate transfusion is a recurring problem year on year. Due to lack of staff awareness patients with sickle cell may be transfused inappropriately or with blood not meeting specific requirements. From data reported to Serious Hazards of Transfusion (SHOT) UK haemovigilance scheme, 2010-2019 98/3506 (2.8%) of all Specific Requirement Not Met errors occurred in patients with sickle cell disorder. The Annual SHOT Report contains a yearly chapter on errors in haemoglobinopathy patients which can be accessed here: <https://www.shotuk.org/shot-reports/>
- **Where care for sickle cell patients does not meet an appropriate standard of care, what are the reasons for this?**
 - This is a significantly underfunded area (especially in comparison for haemophiliac care/cystic fibrosis care, etc). As a result, there are significantly fewer numbers of specialised nurses, doctors, psychologists and support staff that have chosen to work within this service. They mainly move into oncology (white cells) and clotting with research and opportunities. There is known to be a

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shortage of Consultant Haematologists and an even greater shortage of those specialising in red cell disorders. Sickle patients deserve care from a multidisciplinary team with specialist knowledge. Improvements to community services and support are equally important, benefits, welfare, housing may assist with social needs and thus keep patients well and out of hospital

- Lack of awareness amongst general medical/surgical and nursing team
- Lack of awareness of the need to contact specialist teams especially in district hospitals and escalate in a timely manner
- **What training and education do you provide to your members/employees around sickle cell disease? Do you have plans to increase the level of training provided?**
 - Red cell disorders (sickle cell) has and will continue to be chosen as a theme for the biannual RCPATH educational day but we could do more with more targeted training days for specific groups of health care professionals
 - Online training modules can be developed that will be easily accessible with assessment of knowledge – an online Pathology Portal is being developed and this could be potentially incorporated
 - Need to collaborate with key stakeholders and explore funded trainee posts to centres of excellence and funded research opportunities + review of deanery / competencies of junior doctors

For researchers and research funding bodies

- **What research are you undertaking or funding to develop evidence on the best approach to managing patients in sickle cell disease with acute illness?**
- **What improvements have been made to the care provided to sickle cell patients because of past research you have undertaken or funded?**
- **What new evidence is required on how best to treat patients with sickle cell disease using existing treatments?**
- **What new treatment approaches need to be developed to treat acute and chronic complications in sickle cell disease?**