[Insert your name and address here –

this is important to let your MP

know that you are a constituent]

[Insert date here]

Dear [Insert your MP’s name],

**Re: Failures for those living with Sickle Cell**

I am writing with regards to the publication of [‘No One’s Listening’,](https://www.sicklecellsociety.org/no-ones-listening/) a ground-breaking inquiry report conducted by the Sickle Cell and Thalassemia APPG and the Sickle Cell Society. The report highlights avoidable deaths and shocking failures of care for sickle cell patients[[1]](#footnote-2).

Key findings from the inquiry include:

* Evidence of sub-standard care for sickle cell patients admitted to general wards or attending Accident & Emergency (A&E) departments (including a widespread lack of adherence to national care standards)
* Low awareness of sickle cell among healthcare professionals and clear examples of inadequate training and insufficient investment in sickle cell care.
* Frequent reports of negative attitudes towards sickle cell patients and a weight of the evidence suggests that such attitudes are often underpinned by racism.
* The inquiry also found that these concerns have led to a fear and avoidance of hospitals for many people living with sickle cell.

These failings in care have led to patient deaths and ‘near misses’, such as the tragic death of [Evan Nathan Smith](https://www.sicklecellsociety.org/evannathansmith/) in April 2019. The report highlights that high-profile cases of failings like these are sadly not isolated incidents, noting the tragic death of [Tyrone Airey](https://www.mylondon.news/news/sickle-cell-sufferer-singer-songwriter-21730986) in March 2021.

The inquiry heard that sickle cell patients regularly having to educate healthcare professionals about the basics of their condition at times of significant pain and distress. Further, sickle cell patients often reported being treated with disrespect, not being believed or listened to, and not being treated as a priority by healthcare professionals even during cases where urgent medical care was needed. The report concludes that racism underpins many of these negative experiences.

The report includes a number of recommendations and we are asking the government to take the following key steps to ensure that the needs of people with sickle cell are addressed with urgency:

* NHS Trusts to share findings of all internal reviews into incidents involving serious sickle cell care failings with the National Haemoglobinopathy Panel so that learnings can be communicated to haemoglobinopathy teams across the country.
* All NHS Trusts to develop an action plan setting out how they will ensure compliance with the NICE clinical guideline around the delivery of pain relief within 30 minutes for sickle cell patients.
* Royal College of Emergency Medicine and Royal College of Physicians to develop guidance for staff working in A&E and on general wards making clear that sickle cell patients should be prioritised for treatment as a medical emergency due to the high risk of fast medical deterioration, to be distributed by NHS Trusts.
* Health Education England to develop an e-learning module based on the national standards of care developed by the Sickle Cell Society in partnership with clinical experts and the UK Forum on Haemoglobin Disorders, which should be mandatory for all healthcare professionals providing sickle cell care in high-prevalence areas.
* All NHS Trusts to require that haematology teams are informed whenever a sickle cell patient accesses or is admitted to the hospital to ensure the patient’s clinical history is known and advice can be passed on regarding their care, with compliance reported via the NHS England and NHS Improvement Specialised Services Quality Dashboards.
* The Nursing and Midwifery Council and the General Medical Council to urgently commission a review of their approach to sickle cell training, in collaboration with the sickle cell community.
* The NMC and GMC to strengthen requirements around the level of sickle cell training required for university curriculums to be approved.
* Health Education England to provide additional funding for sickle cell training programmes for healthcare professionals, including for training in the delivery of blood transfusions for non-specialist doctors.
* Secretary of State for Health and Social Care to implement charge-free prescriptions for sickle cell patients.
* NHS England & NHS Improvement to provide increased funding for sickle cell services in recognition of the consistent underfunding of sickle cell services when compared with services for other conditions. This should include dedicated funding for NHS Trusts to improve apheresis capacity across the country.
* UK Research and Innovation and the National Institute for Health Research to launch dedicated sickle cell research opportunities, including supporting and funding research into genetic therapies to cure sickle cell disorder.

These steps will help to alleviate the current inequalities that sickle cell patients face through ought the UK. They will also help to restore trust in the health services for those who have been deeply traumatised by negative experiences. They will give voice to the tireless work of sickle cell community organisations and charities in the UK who have been pushing for change – for decades. As a parliamentarian, your support is invaluable.

Yours sincerely,

[Insert your name]

1. Sickle cell is one of the fastest growing genetic blood conditions in the UK with 380,00 carrying the sickle cell gene in the UK. [↑](#footnote-ref-2)