NHS RACE & HEALTH OBSERVATORY



Identifying common themes in preventable deaths of people living with sickle cell

A review of Prevention of Future Death reports on behalf of the NHS Race and Health Observatory

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Summary

This report reviews all Prevention of Future Death (PFD) reports relating to people with sickle cell disease or sickle cell trait issued in England and Wales between 2013 and 2026, to identify recurring themes contributing to preventable deaths and to assess how organisations have responded. Ten PFD reports met the inclusion criteria, relating to ten decedents. Nine reports each concerned one person and one joint report concerned two; one person was the subject of both the joint report and a later report. Eight out of ten decedents had sickle cell disease and two had sickle cell trait. The two people with trait were army recruits who collapsed during extreme exertion in training. Most people with sickle cell trait live normal lives and do not need the care described in this report. Elsewhere in this report, 'people living with sickle cell' refers to people with sickle cell disease. Most decedents were male and most PFD reports were issued in London or Birmingham; causes of death included acute chest syndrome, multi-organ failure, and sepsis, with four deaths occurring in people under 18.

Using the five themes identified in the 2021 APPG/Sickle Cell Society report 'No One's Listening' as a starting framework, this review found that substandard clinical care, lack of joined-up care between teams and care settings, and low awareness of sickle cell among healthcare and other professionals were repeatedly cited by coroners as contributing to deaths. Negative attitudes towards people living with sickle cell and under-resourcing of sickle cell services were less explicitly named by coroners but can be inferred throughout the cases reviewed. A further theme emerged from this analysis: a recurring failure by organisations to adequately investigate, learn from, and share lessons following deaths of people living with sickle cell.

Sixteen organisations were addressed across the ten PFD reports; most had a published response and most proposed concrete action, but publicly available evidence of implementation was limited, and a minority of organisations had no published response at all. This report sets out recommendations aimed at closing the gap between organisational commitments made in response to individual deaths and their sustained, system-wide implementation.

Background

The 2021 Sickle Cell and Thalassaemia APPG/Sickle Cell Society report 'No One's Listening' highlighted avoidable deaths and failures of care for people living with sickle cell in secondary care.[1] Drawing on evidence from patients, families and clinicians, it drew out five themes: substandard care on general wards and A&E; failings in providing joined-up sickle cell care; low awareness of sickle cell among healthcare professionals and inadequate training; negative attitudes towards people living with sickle cell; and inadequate investment in sickle cell care. The report situated these failings within a broader context of health inequality and racism within healthcare, given that sickle cell disease predominantly affects people of African or Caribbean heritage who continue to face disparities in healthcare.

Since then, there have been further preventable deaths of people living with sickle cell. A number of these have resulted in Prevention of Future Death (PFD) reports, also known as Regulation 28 reports. These are issued by coroners in England and Wales when an inquest reveals concerns that could lead to future deaths unless action is taken.[2] PFD reports are addressed to individuals or organisations that the coroner believes has the power to take action to address these concerns. Although recipient organisations are required to respond within 56 days setting out the action they have taken or propose to take, coroners have no power to compel a response, action or evidence of implementation.

PFD reports therefore represent a unique data source to examine the factors that contribute to the preventable deaths of people living with sickle cell. They are issued at the culmination of a formal inquest process and incorporate evidence from clinicians, expert witnesses and often the families of those who have died. They aim to identify system failings which may have relevance beyond the recipient organisations, and if future preventable deaths of people living with sickle cell are to be avoided then their lessons must be learned. However, PFD reports relating to the deaths of people living with sickle cell have not previously been systematically analysed.

This report, commissioned by the NHS Race and Health Observatory, aims to address this gap. It reviews all PFD reports relating to deaths of people living with sickle cell issued since the introduction of the current statutory framework in 2013 to identify common themes contributing to preventable deaths and to characterise organisational responses.



PFD reports aim to **identify system failings** which may have relevance beyond the recipient organisations, and if **future preventable deaths of people living with sickle cell are to be avoided then their lessons must be learned.**

Methods

PFD reports were identified using a searchable online repository and cross-checked against the Courts and Tribunals Judiciary database.[3,4] Reports were searched from 2013 to the present: the start date of 2013 corresponds to the date of introduction of the current statutory framework governing PFD reports. Searches were conducted using the terms 'sickle', 'SCD', 'HbSS' and 'haemoglobinopathy' to account for variation in the terminology used in reports. Duplicate records were removed. Reports were eligible for inclusion if sickle cell disease or trait was listed as a cause of death by the coroner in either part I or part II of the medical cause of death, or if it was cited as contributory in a narrative conclusion. Reports were excluded if sickle cell was mentioned incidentally as part of the deceased's medical history but was not related to their cause of death. The associated organisational responses were also included where available on the Courts and Tribunals Judiciary website. Searches were conducted on the 8th July 2026.

For each included report, the following data were extracted into a standardised template: decedent age, sex and ethnicity where recorded; geographical location based on coronial jurisdiction; cause of death as determined by the coroner; setting in which the death occurred; the full text of the coroner's concerns; and the recipient organisations and whether they responded.

Further analysis of the reports was undertaken using NVivo using a two-stage qualitative approach. In the first stage, reports were read using a directed content analysis approach according to the themes identified in 'No One's Listening' as detailed above.[5] In the second stage, reports were read inductively to identify any additional themes not captured by existing categories. Analysis was undertaken by a single reviewer.

Organisational responses were read initially to determine whether a concrete action had been proposed in response to the PFD report. Where a concrete action was proposed, this was recorded and categorised using categories developed by the reviewer. Publicly available evidence of implementation of these actions was sought via internet searches; where this was unavailable, the reviewer submitted a Freedom of Information (FOI) request to the recipient organisations requesting this evidence.

Results

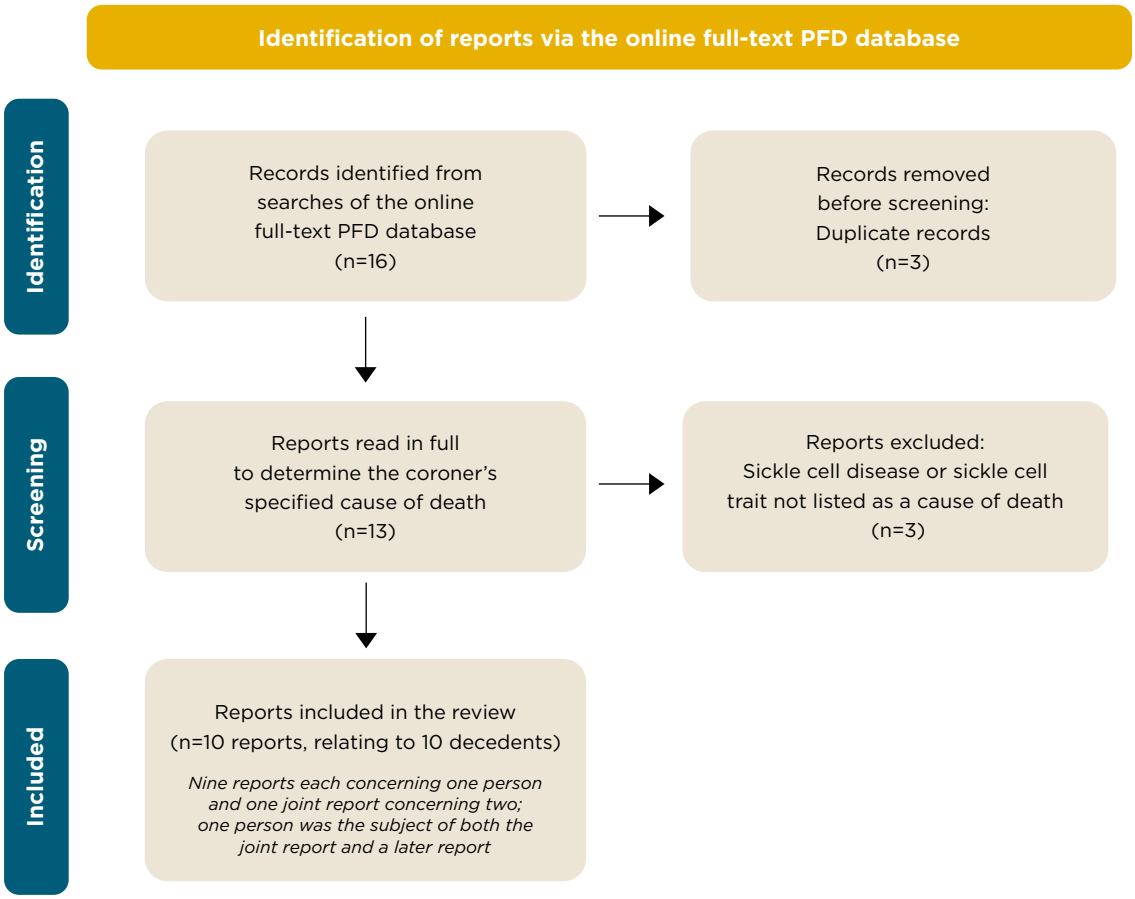

Figure 1: flow diagram of identification, screening and inclusion of PFD reports relating to deaths of people living with sickle cell or sickle cell trait issued 2013-2026.

Searches of an online full-text PFD database returned sixteen results (see Figure 1). Three of these were duplicate records and were excluded. The remaining thirteen were read to determine the cause of death specified by the coroner. Of these, ten had sickle cell disease or sickle cell trait listed as a cause of death and were therefore eligible for inclusion, relating to ten decedents; one of these reports was a joint report concerning two decedents. One PFD report regarding a death in prison made reference to a report by the Prisons and Probation Ombudsman into the same death; as this gave further detail about the circumstances of the death it was also included in analysis.[6] A cross-check against the Courts and Tribunals Judiciary website search function did not retrieve any further PFD reports beyond those already identified.

DEMOGRAPHIC DATA

Data on age, sex, geographical location and cause of death of decedents are presented in Table 1. Four of the ten deaths were in people aged under 18 and most decedents were male. Ethnicity was not recorded for any decedents. 5/10 reports were issued in London. There were a range of causes of death, including acute chest syndrome, multi-organ failure and sepsis. Most people died while inpatients in hospital but one died at home and one while in prison.

Table 1: age, sex, geographical location and cause of death of decedents in PFD reports related to people living with sickle cell issued 2013-2026.

	Number
Age	
Under 18	4
Over 18	6
Sex	
Male	8
Female	2
Geographical location	
London	5
Birmingham	4
Yorkshire	1
Cause of death	
Acute chest syndrome	2
Pneumococcal sepsis	2
Undetermined/not stated	2
Cardiac failure secondary to severe anaemia	1
Intra-abdominal haemorrhage following liver biopsy	1
Multi-organ failure secondary to exertional rhabdomyolysis	1
Peritonitis and shock secondary to perforated duodenal ulcer	1
Location of death	
Hospital	8
Home	1
Prison	1

THEMATIC ANALYSIS

Substandard medical care across care settings

Many PFD reports cited inadequate medical care as contributing to the preventable deaths of people living with sickle cell. This ranged across care settings, from inpatient medical care in hospital to care delivered in institutions such as prisons or the workplace.

Lack of regular clinical assessment or monitoring, including of pain, was regularly cited. One patient's care plan stated they required hourly observations and regular pain assessments, but these were not performed for over six hours. Another acutely unwell patient did not have observations performed for over an hour after arriving in A&E. Coroners cited a lack of consideration for patients' sickle cell disease in determining the frequency or intensity of assessment and monitoring; in one case there was an 'over-reliance on the NEWS algorithm' when assessing a young unwell patient with a sickle cell crisis. In another, a patient living with sickle cell who had just undergone a liver biopsy did not have his sickle cell disease taken into account when monitored post-procedure.

In addition to basic assessment and monitoring, investigations and treatment were delayed or not done at all. In one case, staff disregarded a plan to check a patient's haemoglobin, leading to a delayed blood transfusion; the patient later died of heart failure due to severe anaemia. An unwell patient presenting to A&E did not have bloods taken for several hours despite stating he was in sickle cell crisis; blood tests were not performed until he was in cardiac arrest at which point he was found to be severely anaemic with abnormally high levels of potassium and lactate and a dangerously low blood sugar level. Another patient was not given intravenous fluids for six hours despite this forming part of his care plan. The coroner mentioned that staff had experienced difficulty inserting a cannula to administer fluids but that this problem had not been escalated or resolved.



In one case, staff disregarded a plan to check a patient's haemoglobin, leading to a delayed blood transfusion; the patient later died of heart failure due to severe anaemia.

The above factors meant that deteriorating patients were not recognised and managed appropriately. One patient died in a busy A&E after spending hours in a waiting area while his mother tried to alert staff to his worsening condition; by the time staff realised how unwell he was, he suffered a cardiac arrest and could not be resuscitated. Another patient's critically low haemoglobin level was not recognised until too late.

There was evidence of substandard medical care in other settings beyond hospital. The prison ombudsman report stated that one patient died in prison after telling staff that he could not breathe; no physical assessment or observations were carried out other than a basic visual observation between his initial complaint to prison staff at around 12:30pm and 10:30pm when staff realised he was not breathing, a period of ten hours. His request to see a doctor was also not actioned. Two patients died on separate incidents at an army recruitment centre after collapsing during a timed run. The coroner raised concerns that the centre had no system for obtaining urgent medical attention when required.

Lack of joined-up care

As also highlighted in the 'No One's Listening' report, fragmented and uncoordinated care also contributed to preventable deaths. This was a factor repeatedly cited by coroners and appeared in almost every PFD report reviewed.

There was a lack of coordination between teams on multiple levels and across multiple care settings. Care was not coordinated between teams within the same hospital: for example, a patient living with sickle cell undergoing liver biopsy was not discussed between the gastroenterology and haematology teams despite awareness of his sickle cell disease.

There was repeated evidence of inadequate coordination between primary and secondary care. Two children living with sickle cell died from pneumococcal sepsis after a breakdown in communication and coordination between their GPs and hospital teams. One of the children subsequently was not prescribed prophylactic penicillin and the other did not receive the pneumococcal vaccination, both essential components of care for people living with sickle cell who are more vulnerable to certain types of bacterial infection. Care was also inadequately coordinated between secondary and tertiary care. In one case, a child was admitted to a hospital without specialist paediatric haematology; the coroner cited the absence of a clear protocol and shared-care pathway between this hospital and the regional tertiary centre as contributing to the child's subsequent death.

Poorly coordinated care left people living with sickle cell without someone who held overall responsibility and accountability for their care, with the result that key parts of their care were missed. In the cases of the two children who died of pneumococcal sepsis, it was unclear whether the GP or the hospital team were leading on specific aspects of their care. In the case of the person living with sickle cell who died in prison, the prison ombudsman commented that it was unclear in the final hours of his life whether the physical health nurse or mental health nurse was responsible for assessing him, with the ultimate result that no health assessment was performed at all. Regarding one person with sickle cell trait who died during army recruitment, the coroner commented that there was a lack of overall medical expertise and guidance on who was responsible for carrying out further risk assessments and preventive action. They cited the involvement of a private company in the recruitment process as exacerbating this, creating two parallel clinical and occupational health structures in the company and the army which did not always coordinate or communicate well.

In some cases, care was not joined up because care plans or guidelines were not referred to or did not exist. One person living with sickle cell and other complex health needs including cerebral palsy was admitted to hospital with an individualised care plan and health passport, the existence of which were flagged by a warning on his electronic health record. His care plan was available to staff but was 'hard to locate' and not consulted; his health passport was not available to staff until the day after admission. Key aspects of his care plan were not carried out. In two cases, coroners cited unclear or absent national guidance as contributing to the deaths of people living with sickle cell. In the case of a child living with sickle cell who died from a perforated duodenal ulcer, the coroner was concerned about the absence of national consensus about whether children living with sickle cell who are prescribed non-steroidal anti-inflammatory pain relief (NSAIDs) such as ibuprofen should also be prescribed medication to protect their gastro-intestinal tract from the known irritant effect of these medications. In the case of a person living with sickle cell who died following liver biopsy, the coroner pointed out that both the hospital's local standard operating procedure for liver biopsy and the UK's national liver biopsy guidelines, published jointly by the British Society of Gastroenterology, the Royal College of Radiologists and the Royal College of Pathologists, do not give adequate consideration to patients with haematological disorders such as sickle cell.

> "Highlighted in the 'No One's Listening' report, fragmented and uncoordinated care also contributed to preventable deaths. This was a factor repeatedly cited by coroners and appeared in almost every PFD report reviewed."

Lack of awareness

Lack of awareness around sickle cell was also repeatedly cited by coroners as contributing to preventable deaths. This encompassed a lack of awareness around sickle cell crisis and its management; a lack of awareness around the condition more broadly and the risks it poses; and a lack of awareness of individual patients' sickle cell disease which negatively impacted their care.

As also highlighted in the 'No One's Listening' report, lack of knowledge and awareness of sickle cell crisis and how to manage it was a repeated factor in substandard care and subsequent death. In the case of one child who died of severe anaemia, the coroner raised concerns that staff had a lack of knowledge and appreciation for the signs and symptoms of a sickle cell crisis. Another patient who died after presenting acutely unwell to A&E had partial observations done in accordance with the NEWS2 algorithm, which were within normal range. The coroner observed that staff were over-reliant on this and did not take into account other worrying signs, such as acute pain which could not be managed at home and the patient himself stating that he was in sickle cell crisis. The death of a person living with sickle cell in prison after he was restrained and told staff he could not breathe prompted the prison ombudsman to comment that prison and custodial staff nationally may not have a proper understanding of how to identify a sickle cell crisis or of the associated risks.

Inadequate understanding of sickle cell went beyond crisis recognition and management. Commenting on the death of an army recruit with sickle cell trait who collapsed during selection, the coroner stated that army recruitment medical staff were not adequately trained in sickle cell or in other disorders which may be prevalent in recruits born outside the UK. They also specifically highlighted the inclusion of 'cola-coloured urine' in army medical guidance as a sign of sickle cell. Cola-coloured urine can be a sign of the excessive breakdown of red blood cells in the body, which can be a complication of sickle cell disease, but it can also be caused by several other things and is not diagnostic of sickle cell. The coroner commented that this reflected 'gaps in clinical understanding' around sickle cell.

In one case, lack of awareness that a person was living with sickle cell was cited as contributory to their death. This was the case of a child who repeatedly attended her GP practice with symptoms of respiratory infection and was seen by three different GPs, none of whom displayed awareness of her background of sickle cell disease despite it being in her available medical records. Failure to appreciate this contributed to a failure to recognise that she was not prescribed prophylactic penicillin and following a further respiratory deterioration she died in hospital from pneumococcal sepsis.

Negative attitudes towards people living with sickle cell

The 'No One's Listening' report described widespread negative attitudes towards people living with sickle cell, including prejudice, disrespect and disbelief when trying to access care. It highlighted that racism is a key factor in the substandard care received by many people living with sickle cell.

Although coroners did not always explicitly cite negative attitudes towards people living with sickle cell as contributing to preventable deaths, this theme can nevertheless be traced throughout these PFD reports and can be seen to play a role in several deaths. People living with sickle cell and their families did not have their concerns listened to or taken seriously. In one case, a patient's mother asked A&E staff repeatedly for help with her deteriorating son, only to be dismissed and told that staff had more unwell patients to attend to. The coroner cited a lack of 'compassion and curiosity' as contributing to his death. A person living with sickle cell who died in prison told staff that he could not breathe after being restrained and moved to a segregation unit but did not receive any formal medical assessment and was not allowed to see a doctor despite requesting to.

A lack of concern for the risks associated with sickle cell and failure to take those risks seriously can also be seen as part of a broader dismissive attitude towards people living with sickle cell. In the case of the two army recruits who died while undergoing selection, the coroner raised concerns that even after their deaths when the army had issued new guidance around the risk of sickle cell and exertional collapse, candidates with a known risk of sickle cell were still being directed to complete the strenuous timed run.





Lack of resources

Lack of resources specifically dedicated to sickle cell care was cited in only one case. This was a child who was admitted to a district general hospital without specialist paediatric haematology leading to delays in obtaining a specialist opinion from the regional tertiary centre. At the inquest, the coroner was told that a 'hub and spoke' model for shared care of people living with sickle cell had been discussed in the region but that this had not been put in place yet due to lack of funding.

However, the broader impact of an under-resourced health system can be seen in other cases. In the case of a young man who died after lack of prompt assessment in A&E, the coroner pointed to congestion in the department and staff workload as contributing to his death. Although such clinical pressures pose a risk to all patients, the other factors contributing to preventable deaths in people living with sickle cell - inadequate monitoring and assessment, lack of coordination, lack of awareness and negative attitudes - mean that they are highly vulnerable to falling through the gaps in under-resourced and high-pressure clinical environments.

Inadequate incident reporting, investigation and organisational learning

A final theme highlighted by coroners across the PFDs was that where deaths have occurred, organisations were falling short in how they reported, investigated and learned from these.

This was most comprehensively described in the PFD regarding the death of an army recruit with sickle cell trait from exertional collapse during participation in a timed run. The coroner noted several failings in the institutional response, including a failure to report the incidents to the relevant investigatory bodies, failures in how the incidents were investigated and that similar exercises were not paused while an investigation was carried out, and structural issues within the governance bodies with oversight of incident reporting and investigation. The coroner noted that since this death, and that of another recruit with sickle cell trait, there had been a substantial number of further 'near misses' and that the army and its private recruitment provider had not taken adequate steps to safeguard recruits, demonstrating a lack of organisational learning.

With regards to the prison estate and the death of a person living with sickle cell following restraint and segregation, the coroner commented in a PFD that although the healthcare provider in the relevant prison had made several improvements in practice since his death, they were concerned that this work was not being shared and replicated nationally. This raises the issue that where local improvements may be made in response to the deaths of people living with sickle cell, these are not being communicated or shared nationally, leading to further fragmentation and variation in care.

ORGANISATIONAL RECIPIENTS AND RESPONSES

All PFDs are addressed to recipient organisations who the coroner believes has the power to take action to prevent further deaths. The ten PFDs related to deaths of people living with sickle cell were addressed to a variety of organisations, from individual healthcare providers to national bodies. Most (8/10) were addressed to more than one organisation, showing that most deaths were due to multiple factors involving several different organisations. Overall, sixteen organisations were named as recipients. Table 2 shows the types of organisations addressed and how many organisations of each type were contacted. The most frequently contacted type of organisation were government departments and agencies, which included the Department of Health and Social Care and NHS England. This is perhaps because in issuing a PFD, coroners are aiming to effect systemic change and therefore address PFDs to the national bodies who they feel are best placed to oversee this.

Table 2: frequency of type of recipient organisation addressed by PFDs relating to deaths of people living with sickle cell issued 2013-2026.

Type of organisation	Number of recipient organisations
Government departments and agencies	5
GP practices	3
Hospital trusts	3
Professional medical organisations	3
Local commissioning organisation	1
Private company	1

Some organisations were contacted more than once during the 13-year period. Taking this into account, overall, there were 22 instances in which an organisation was addressed by a PFD relating to the death of a person living with sickle cell. Of these, only 13/22 (59%) resulted in a published response which proposed concrete action. This represented published responses by 10 organisations (three organisations responded twice proposing concrete action).

Figure 2: responses of organisational recipients of PFDs relating to the death of a person living with sickle cell issued 2013-2026.



Organisations proposed a range of actions in response to PFDs relating to the deaths of people living with sickle cell. Staff training was commonly discussed: for example, NHS England proposed a three-year training and development programme across prison staff in London, to be delivered in conjunction with the Sickle Cell Society. Primary and secondary care providers committed to increased staff training around sickle cell and sepsis. Notably, one organisation went beyond training in sickle cell itself to consider the need for and propose cultural competency training. Several organisations described organising seminars and other events to disseminate information around sickle cell, including learning arising from deaths of people living with sickle cell; these could be targeted at specific professional groups or at regional and national forums such as commissioning forums. Several respondents also proposed using existing communication channels such as newsletters or developing new resources such as websites to help disseminate information to staff and patients about sickle cell disease.

Another frequently proposed action was to update organisational policies and procedures. This could be to include consideration of sickle cell in a policy where previously it was absent, or to improve a sickle cell-related policy or procedure that had been deemed inadequate. Several organisations described making use of digital tools to facilitate this, including electronic letter templates, automated alerts in electronic health records and shared electronic care plans. Relatedly, several organisations committed to review or update their clinical guidelines and escalation pathways or implement established sickle cell alert pathways such as the ACT NOW acronym. Many organisations planned to deliver parallel training on these updated guidelines.

Some organisations responded by proposing changes to staffing, either by creating new roles or changing existing job roles and responsibilities. This included, for example, the appointment of a haemoglobinopathy governance lead at one hospital. In another example,

the haemoglobinopathy education lead took on responsibility for disseminating key clinical and policy updates via newsletters. In another, a system was developed where the haemoglobinopathy CNS took responsibility for ensuring that patient care plans were updated and reviewed on discharge. Several organisations also described forming new working groups or steering groups comprising existing staff in order to address the issues raised by the PFDs.

Finally, organisations described using existing governance structures or establishing new ones to ensure ongoing compliance and continue to disseminate learning from incidents. This included regular audit programmes, haematology mortality and morbidity meetings, root cause analyses and serious incident reports. Several organisations committed to sharing future audit findings with the coroner. However, although some organisations described creating a sustainable audit structure, others committed only to a one-off audit at an unspecified point in time, raising the question of how ongoing compliance will be assured and how change will be embedded within the organisation.

IMPLEMENTATION

Of the 10 organisations with published responses proposing actions in response to PFDs relating to deaths of people living with sickle cell, five provided evidence of implementation: two in response to a Freedom of Information Act (FOI) request (the MHRA and Barts Health NHS Trust) and three voluntarily following an informal request (Homerton Healthcare NHS Foundation Trust, Maylands Healthcare Surgery and the British Society of Gastroenterology, which as a charity is not subject to FOI). Two organisations (NHS England and the Ministry of Defence) refused FOI requests on cost grounds under section 12 of the Act. Two (the Partnership of East London Co-operatives and Sheffield Teaching Hospitals NHS Foundation Trust) did not respond within the statutory period. One (Capita plc) is not a public authority and is therefore not subject to FOI. Neither a refusal on cost grounds nor the absence of a response is evidence of non-implementation.

Discussion

This report reviews all PFDs relating to deaths of people living with sickle cell issued between 2013 and 2026. It summarises demographic data of the decedents and reviews their causes of death as determined by the coroner. Thematic analysis of the factors cited by coroners as contributing to preventable deaths shows that substandard clinical care, lack of joined-up care, lack of awareness of sickle cell, negative attitudes towards people living with sickle cell and inadequate reporting, investigating and learning from deaths all play a role. On review of organisational recipients and responses, most organisations addressed by these PFD reports had responses to the coroner published and most of these responses did propose concrete action. However, publicly available evidence of implementation and ongoing audit was limited.

This report takes as its starting point the themes identified by the 2021 Sickle Cell and Thalassaemia APPG report entitled 'No One's Listening'. Analysis of the PFD reports according to those themes found that many coronial concerns echoed the concerns raised in that report. Coroners repeatedly identified the themes of substandard care, lack of joined-up care and lack of awareness of sickle cell disease, and these themes continued to be cited in PFD reports issued after the publication of the APPG report in 2021. Several of these themes were also identified in a 2008 review by NCEPOD into deaths of people living with sickle cell disease, 'A sickle crisis?', which also highlighted substandard care (especially inadequate assessment and monitoring), lack of joined-up care and lack of awareness of sickle cell.[7]

Coroners less frequently or explicitly identified negative attitudes towards people living with sickle cell or lack of resources for sickle cell. As discussed above, negative attitudes towards people living with sickle cell can be inferred from several of these PFD reports even when not explicitly mentioned. The relative absence of lived experience voices from the coronial process may explain in part why prejudice, racism and disrespectful attitudes are not explicitly mentioned; by contrast, the APPG report benefited from the involvement of several people living with sickle cell. None of the PFD reports reviewed mentioned racism. However, as the 'No One's Listening' report makes plain, racism is a major factor in the substandard care and negative attitudes experienced by people living with sickle cell. It is likely that racism underpins many of the factors contributing to the preventable deaths of people living with sickle cell included in these PFDs. This includes the treatment of individual patients who were dismissed or not taken seriously but also institutional racism which leaves sickle cell under-resourced and under-researched. The absence of any explicit mention of racism is striking and perhaps suggests that the coronial process is not sufficiently sensitive to the impact of racism on preventable harm and death. This may in part be due to a lack of diversity among coroners; the lead coroner for diversity in England and Wales recently highlighted that inadequate data is frustrating efforts to broaden access to the profession.[8]

This report also identifies a theme emphasised more strongly by coroners: inadequate organisational learning from deaths. This is critical to prevent future deaths of people living with sickle cell. The very issuance of a PFD report of course implies that an organisation has not adequately responded to the death of a person living with sickle cell. In this context it is especially notable that, in a minority of instances in which an organisation was contacted by the coroner, no response was published. The PFD report process remains an important tool for coroners to highlight factors that organisations can change, but coroners have limited powers to compel a response, action or implementation. This has led to organisations and campaigners such as INQUEST to call for an independent National Oversight Mechanism to collate, analyse and track responses to inquests and PFD reports.[9]

PFD reports have several limitations as a data source. Not all preventable deaths of people living with sickle cell are necessarily referred to a coroner. Even when they are, the decision to issue a PFD report is subjective and the threshold may vary by coronial jurisdiction. Bias and racism may also factor into the decision to refer to coroners or to issue a PFD report. Coroners issue PFD reports when they believe that a systemic problem needs to be addressed in order to prevent future deaths and that a specific organisation has the power to do so; therefore, they may not issue one if they do not believe that an issue can be resolved by a specific organisation, or if the preventable death was due to the actions of an individual. For example, no PFD report was issued in the high-profile death of Evan Nathan Smith, who died aged 21 in April 2019 at North Middlesex Hospital and whose inquest identified preventable factors contributing to his death, including a delayed blood transfusion.[10] In short, PFD reports represent a narrow sample of preventable deaths from sickle cell and an even narrower sample of all deaths from sickle cell and cannot be taken as representative. This is complicated further by the fact that national mortality data for sickle cell are not routinely published or analysed by ethnicity. Ethnicity has been recorded as part of death certification in England and Wales since September 2024, but coroners are only expected to record it where it is already known to them,[11] and this review could not examine preventable deaths by ethnicity because these data are not linked to inquests or PFD reports. Another limitation of this report is that searching and selection of PFD reports was performed by a single reviewer; however, two databases were used for cross-checking (the Courts and Tribunals Judiciary website search function and the searchable online repository Death Lessons).

However, they also have several strengths. They represent the culmination of an inquest process which will have heard detailed evidence regarding a death, including from people directly involved and often including the families of those who have died. Coroners are experienced in reviewing deaths and in identifying when things have gone wrong and could be prevented from reoccurring. PFD reports are therefore a useful resource to consider how and why people living with sickle cell may die preventable deaths, while acknowledging the limitations above.

Recommendations

1. Track and share learning from the deaths of people living with sickle cell.

NHSRHO supports calls from INQUEST and others for an independent National Oversight Mechanism to collate, analyse and track responses to inquest findings and PFD reports.[9] NHS England and DHSC should establish a sickle cell-specific mechanism, building on the National Haemoglobinopathy Panel's existing reporting of deaths by specialist and local haemoglobinopathy teams, to collate learning from deaths of people living with sickle cell: PFD reports and organisational responses, Patient Safety Incident Response Framework (PSIRF) responses, Learning from Deaths reviews and Medical Examiner findings. This should be disseminated to haemoglobinopathy coordinating centres, acute trusts, primary care and relevant non-NHS settings such as prison healthcare.
The mechanism should also track whether actions proposed in organisational PFD responses have been implemented. It should also record each person's sickle cell genotype.

Rationale:
9 of 22 instances (41%) in which an organisation was addressed by a PFD relating to the death of a person living with sickle cell did not result in a published response proposing concrete action. Evidence of implementation was rarely publicly available and was not always available on Freedom of Information request. In one case a coroner raised specific concerns that local improvements made in response to the death of a person living with sickle cell were not being shared nationally.

Lead:
UK Government and Ministry of Justice (National Oversight Mechanism); NHS England/DHSC with the National Haemoglobinopathy Panel and haemoglobinopathy coordinating centres (sickle cell mechanism).

Timescale:
Sickle cell mechanism in place within 12 months, with an annual published summary thereafter.

Measure of success:
An annual published summary of deaths of people living with sickle cell reviewed, PFD reports issued, and the implementation status of each proposed action.



2. Make full use of the ethnicity data collected at death certification

Since September 2024, ethnicity has been recorded as part of death certification in England and Wales.[11] Recording it again in PFD reports would duplicate this. Instead, the data already being collected should be completed, linked and published:

(a) Recording. When a coroner investigates a death, the coroner certifies it, and the form they use now includes an ethnicity field. However, coroners are only expected to complete it where the information is already known to them.[11] The Chief Coroner should revise guidance so that coroners complete the field from the medical record wherever it is available.

(b) Publication. The Office for National Statistics and Ministry of Justice should publish how completely ethnicity is recorded for deaths investigated by a coroner. They should also link death registration data to inquest conclusions and PFD reports, so that it is possible to see, by ethnicity, which deaths lead to an inquest and which lead to a PFD report.

(c) Sickle cell. The Office for National Statistics should publish mortality data for sickle cell by ethnicity.

Rationale:

Sickle cell predominantly affects people of African and Caribbean heritage, yet this review could not examine preventable deaths by ethnicity, because no published data link ethnicity to inquests or PFD reports. National mortality data for sickle cell are not routinely published or analysed by ethnicity, and in 2025 one in five registered deaths had no known ethnicity recorded.[12] The data needed to examine the differential burden of preventable death exist only if the field is completed and the data are linked and published.

Lead:

Chief Coroner for guidance to coroners; Office for National Statistics and Ministry of Justice for linkage and publication.

Timescale:

Guidance revised, and completeness of ethnicity recording for deaths investigated by a coroner published, within 12 months; analysis of inquests and PFD reports by ethnicity within 24 months.

Measure of success:

Proportion of deaths investigated by a coroner with a known ethnicity recorded; ethnicity breakdown of inquests and PFD reports included in published coroner statistics; sickle cell mortality published by ethnicity.



3. Make individualised care plans visible at the point of care

All NHS trusts should ensure that every person living with sickle cell known to the trust has an individualised care plan, developed and regularly updated in partnership with them, that is immediately visible at the point of care through an electronic patient record alert with a direct link to the plan. Each trust should name an individual responsible for care plans (for example, the haemoglobinopathy lead or clinical nurse specialist) and audit their availability and use.

Rationale:

In one case an individualised care plan existed and was flagged on the patient's record but was 'hard to locate' and not consulted, and key elements of it were not delivered. The trust's response (an electronic alert with a direct link, review of the care plan at discharge, and regular audit) offers a model for others.

Lead:

NHS trusts, overseen by haemoglobinopathy coordinating centres.

Timescale:

Within 12 months, with annual audit.

Measure of success:

Proportion of people living with sickle cell with a care plan reviewed in the past 12 months; proportion of emergency attendances and admissions where the care plan was accessed, reported to the haemoglobinopathy coordinating centre.



4. Make responsibility for antibiotic prophylaxis and vaccination explicit

All specialist haemoglobinopathy teams should state explicitly who is responsible for prescribing and monitoring antibiotic prophylaxis and vaccinations, using a standardised electronic template. GP practices should record this responsibility and act on it. Specialist teams and community organisations such as the Sickle Cell Society should continue to help patients understand the importance of penicillin prophylaxis and vaccination.

Rationale:

Two children died of pneumococcal sepsis after a breakdown in communication between primary and secondary care. In one, prescribed penicillin prophylaxis was never collected or given; in the other, four hospital letters requesting pneumococcal vaccination were not acted on.

Lead:

NHS trusts and haemoglobinopathy coordinating centres; GP practices; integrated care boards.

Timescale:

Within 12 months.

Measure of success:

Audit of specialist letters specifying prescribing responsibility; proportion of children living with sickle cell with documented penicillin prophylaxis and up-to-date pneumococcal vaccination.



5. Strengthen guidance and training on recognising and managing the unwell person living with sickle cell

The Royal College of Emergency Medicine and Royal College of Physicians should review guidance on recognising and managing the acutely unwell person living with sickle cell, including the limitations of early warning scores such as NEWS2, and ensure it is circulated to NHS trusts. All NHS trusts, not only those in areas of high prevalence, should ensure that clinical staff in emergency, acute and primary care receive training based on this guidance. Training should extend to non-NHS settings where people living with sickle cell may become acutely unwell, including custodial settings and military recruitment. Training should draw on existing tools such as ACT NOW, a sickle cell crisis response acronym evaluated in 19 sites across England including HMP Pentonville.

Rationale:

Coroners cited staff lack of knowledge of the signs of sickle cell crisis and over-reliance on the NEWS algorithm. Deaths occurred outside hospital, and the Prisons and Probation Ombudsman raised concern that custodial staff may not understand how to identify a sickle cell crisis.

Lead:

Royal College of Emergency Medicine and Royal College of Physicians (guidance); NHS trusts and NHS England (training); HM Prison and Probation Service and Ministry of Defence (non-NHS settings).

Timescale:

Guidance reviewed within 12 months; training in place within 24 months.

Measure of success:

Updated guidance published; proportion of relevant staff trained, including through induction and mandatory training.

Declaration of interests

EC has no interests to declare.

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Supplementary Materials

Table 1: PFD reports relating to the deaths of people living with sickle cell, 2013-2026.

Name	Date Issued	Age	Sex	Geographical Location	Cause of Death	Location of Death	Circumstances of Death	Coronial concern	Recipient organisations
Emmanuel Akinmuyiwa	26 Sept 2014	7	Male	Birmingham	1a Cardiac failure 1b Severe anaemia 1c Sickle cell disease	Hospital	Admitted in sickle cell crisis with Hb 5.7. Scheduled repeat Hb check skipped as 'looked clinically well'. Hb finally rechecked and found to be critically low (2.8); transfusion given that evening. Collapsed and died shortly after. Death contributed to by neglect.	No clear West Midlands protocol for SCD management. Staff lacked knowledge of crisis signs/symptoms. Hub-and-spoke model discussed locally but unfunded.	NHS England Commissioning groups
Akua Anokye-Boateng	9 May 2014	7	Female	London	1a Acute peritonitis and shock 1b Perforated duodenum 1c NSAID ingestion and Helicobacter-associated chronic duodenal ulceration in SCD	Hospital	Well-controlled SCD. Brief illness followed by sudden collapse and death despite resuscitation. A single NSAID dose earlier in her history contributed to chronic GI ulceration.	No consensus/guidance on routine GI protection (e.g. PPIs) alongside short-term NSAID use in children with SCD. Treating consultant unaware of single-dose risk.	MHRA
Wayne Bayley	31 Oct 2024	43	Male	London	1a Acute chest syndrome 1b Hypoxia and chronic sickle cell lung disease 1c Sickle cell disease and restraint	Prison	Died after physical restraint in custody. Jury narrative conclusion found death contributed to by neglect.	Good local practice developed post-death not known to have been shared nationally across the prison estate. Risk of inconsistent understanding of sickle cell crisis among prison staff generally.	NHS England Ministry of Justice
Kamil Iddrisu*	6 Dec 2019	25	Male	Birmingham	Narrative conclusion only, MCCD not recorded	Hospital	Collapsed during a run as part of military selection assessment. Transferred to hospital but died.	No routine screening of non-UK candidates for sickle cell trait.	Ministry of Defence Capita
Youngson Nkhoma*	6 Dec 2019	30	Male	Birmingham	1a Multi-organ failure 1b Exertional rhabdomyolysis 1c Sickle cell trait II Hypertrophic cardiomyopathy	Hospital	Collapsed during the 2km best-effort run in military selection. Taken to ICU but died same day. Preceded by three prior collapses (including a previous death) that were not connected or acted on in time.	No SCT screening and inadequate institutional awareness of ethnicity-linked risk. Failed/duplicated incident reporting systems. Inconsistent screening across Army/Navy/Air Force. No on-site emergency escalation system. Near-misses post-death not investigated.	Ministry of Defence Capita
Kingsley Imafidon	11 Oct 2024	Not stated	Male	London	1a Intra-abdominal haemorrhage 1b Post liver biopsy for jaundice 1c Liver cirrhosis II Sickle cell disease	Home	Underwent scheduled liver biopsy to investigate suspected cirrhosis. A device used during the biopsy was deployed outside the liver, causing internal bleeding. Discharged after standard 4-hour observation and found unresponsive at home days later.	No liaison between teams regarding HbSS status before biopsy. Trust SOP didn't address patients with other pathologies like HbSS. National liver biopsy guidelines don't address SCD as a comorbidity.	Homerton Healthcare NHS Foundation Trust British Society of Gastroenterology Royal College of Radiologists Royal College of Pathologists

Urielle Kuyenga	9 Dec 2025	4	Female	London	1a Streptococcus pneumoniae sepsis 1b Sickle cell disease (HbSS)	Hospital
Dave Onawelo	27 Aug 2024	34	Male	London	1a Acute respiratory failure 1b Acute chest syndrome 1c Sickle cell disease	Hospital
Johan Pambou	20 April 2017	Not stat-ed	Male	Birmingham	1a Pneumococcal septicaemia II. Sickle cell disease	Hospital
Darnell Smith	18 March 2024	22	Male	Yorkshire	Narrative conclusion only, MCCD not recorded	Hospital

Died of sepsis from bacterial pneumonia. Prophylactic penicillin (prescribed for her SCD) never collected or administered due to breakdown in communication between her mother, GP and hospital. Presented with respiratory symptoms three times in preceding weeks without clinicians identifying her SCD diagnosis. Natural causes contributed to by neglect.	Breakdown in communication over who was responsible for monitoring penicillin dispensing. Repeated failure by GPs to identify her SCD diagnosis from available records.	Partnership of East London Co-operatives Maylands Healthcare Surgery Barts Health NHS Trust Department of Health and Social Care
Declined hospital attendance after first ambulance assessment but returned later with worsening symptoms. Long delay before examination in ED. Mother's concerns dismissed by a nurse. Deteriorated, seized, and had a cardiac arrest; resuscitation unsuccessful.	Failure to identify a critically ill patient with SCD as high-risk. Earlier fluids, transfusion and antibiotics likely would have avoided death. Patient congestion, over-reliance on NEWS algorithm, and "lack of compassion and clinical curiosity" cited as contributing factors.	Barts Health NHS Trust Department of Health & Social Care
Admitted with abdominal and joint pain in sickle crisis and deteriorated over several days despite transfusion and antibiotics. Transferred to Birmingham Children's ITU, diagnosed with pneumococcal septicaemia and died. Contributed to by not receiving a recommended pneumovax23 vaccination.	GP practice had no system to act on repeated hospital letters (4 sent, none actioned) requesting the vaccine. Vaccine itself reported unavailable when sought.	GP practice (name redacted) NHS England
Admitted with reduced appetite, cough, and no bowel movements for 5 days. Had cerebral palsy, scoliosis, SCD, and epilepsy, and required an individualised care plan. Observations, fluids and pain monitoring required by that plan were not delivered for 6-12 hours before critical care admission. Deteriorated, required ventilation, developed pneumonia and respiratory failure, then died over two weeks later.	Individualised care plan was flagged on records but "hard to locate" and not consulted by treating staff despite the flag.	Royal Hallamshire Hospital

* Note that Kamil Iddrisu and Youngson Nkhoma were the joint subjects of the PFD report issued in 2019; Youngson Nkhoma was then the subject of a further PFD report issued in 2022.

Table 2: organisational recipients and responses to PFD reports relating to the deaths of people living with sickle cell, 2013-2026.

Name	Recipient organisation(s)	Response published	Date of response(s)	Actions proposed	Type of action(s)	Evidence of implementation
Emmanuel Akinmuyiwa	NHS England Local commissioning groups	No	N/A	N/A	N/A	N/A
Akua Anokye-Boateng	Medicines and Healthcare products Regulatory Agency	Yes	18 Jul 2014	• Article in 'Drug Safety Update' bulletin (Sept 2014) reminding healthcare professionals that GI side-effects of NSAIDs can be serious/life-threatening, can occur with short-term use, and can occur even in those considered low risk (including children) • Strengthen patient/parent information leaflets for all NSAIDs on recognising GI side-effects and what action to take, within 12 months • Pharmacovigilance Expert Advisory Group of the Commission on Human Medicines consulted; concluded no change warranted to existing warnings or gastro-protective agent guidance	Professional communication/bulletin Patient information update	Received via FOI request
Wayne Bayley	NHS England	Yes	18 Dec 2024	• 3-year training programme with the Sickle Cell Society for healthcare and prison staff across London Health & Justice region (staff training, prison staff training, patient engagement) • Pilot of 'ACT NOW' sickle cell crisis response acronym at HMP Pentonville, for wider rollout • Review of NHS England service specifications to strengthen requirements on long-term conditions incl. sickle cell • Case to be presented to Health and Justice Oversight Delivery Group (HJDOG) for national/regional sharing • All Regulation 28 reports discussed nationally via the Regulation 28 Working Group	Training/education programme Policy/specification review Governance	No response to FOI request within the statutory period
	HM Prison and Probation Service (HMPPS), Ministry of Justice	Yes	3 Feb 2025	None	N/A	N/A
Kamil Iddrisu and Youngson Nkhoma	Ministry of Defence Capita plc	Yes (joint response)	30 Jan 2020	• Two-stage Sickle Cell Trait (SCT) screening for all Army candidates (Family Origins Questionnaire, then blood test) • Suspension/hold on 2000m run for at-risk candidates pending screening • 4-week bespoke pre-conditioning course (Soldier Development Course) for SCT-positive candidates • Interim Training Directive issued to training staff on recognising/treating Exertional Collapse Associated with SCT (ECAST) • Heart-rate monitor use and revised policy on exertional collapse	Screening process change Training/education Policy revision	MoD: FOI request refused under s12 Capita: not a public authority

Youngson Nkhoma	Ministry of Defence Capita plc	Yes (joint response)	19 Dec 2022	• Additional control measures so no candidate attends Assessment Centre before FOQ/blood test results known • Review of all 12 identified 'near miss' incidents; enhanced staff training at affected sites • SCT screening across Army, Royal Navy and RAF by Jan 2023 • Standardised coloured wristbands (and bibs) to identify SCT-positive candidates across all services • Review of wording on 'cola coloured urine' in policy regarding SCT • Recruiting Group Clinical Oversight Board membership extended; Joint Lessons Learnt Panel established • New incident reporting system replacing legacy system	Policy/governance change Incident reporting system change	MoD: FOI request refused under s12 Capita: not a public authority
Kingsley Imafidon	Homerton Healthcare NHS Foundation Trust	Yes	28 Nov 2024	• Elective Liver Biopsy SOP amended: higher-risk patients (incl. known bleeding disorders) must be discussed at North East London Network Liver MDT before biopsy • Higher-risk patients to attend pre-assessment clinic prior to biopsy • New electronic template created for pre-assessment clinic; SOP signposted at booking and reporting stages	Standard Operating Procedure (SOP) update Process change	Received via informal request
	British Society of Gastroenterology	Yes	5 Dec 2024	• Advice on bleeding risk in sickle cell disease patients undergoing liver biopsy to be published in a peer-reviewed journal within 3 months • Advice to be circulated via BSG newsletter to all members within 1 month • Principle to be considered ahead of scheduled 5-year revision of the national liver biopsy guideline	Guidance/publication Member communication	Received via informal request
	Royal College of Radiologists	Yes	12 Dec 2024	None	N/A	N/A
	Royal College of Pathologists	Yes	6 Jan 2025	None	N/A	N/A
Urielle Kuyenga	Barts Health NHS Trust (Haemoglobinopathy Coordinating Centre, Royal London Hospital)	Yes	Not dated on letter	• Family-facing information website in development (clinical info, signposting) • Haemoglobinopathy education lead appointed; GP webinars on managing SCD, Universal Care Plans (UCP) and infection risk (including penicillin V) • Standardised generic letter template for parents/GPs/community teams on prescribing responsibility • GP escalation pathway updated to include sepsis; 'ACT NOW' acronym adopted network-wide • HCC governance lead appointed; audit of care transfers; cultural competency training	Education/training IT/systems integration Governance and audit	Received via FOI request
	Maylands Healthcare Surgery (GP practice)	Yes	20 Jan 2026	• Annual practice-wide audit of patients with sickle cell disease and proactive annual medication review (incl. penicillin V compliance) • Direct liaison with secondary/tertiary care where prescribing responsibility unclear • Sickle cell patients moved to electronic repeat dispensing; pharmacy to flag uncollected prescriptions • Clinical record pop-up alerts for sickle cell diagnosis added • Mandatory sepsis training completed by all clinical staff • Significant Event Analysis (SEA) findings shared with staff and the Coroner	Practice-level clinical process and IT system changes Staff training	Received via informal request

	Partnership of East London Co-operatives	Yes	Not dated on letter
	Department of Health and Social Care (DHSC)	Yes	28 Jan 2026
Dave Onawelo	Barts Health NHS Trust DHSC	No	N/A
Johan Pambou	NHS England	Yes	28 Jun 2017
	GP practice (name redacted)	No	N/A
Darnell Smith	Sheffield Teaching Hospitals NHS Foundation Trust (encompassing Royal Hallamshire Hospital)	Yes	10 May 2024

• Records-review requirement for children/vulnerable adults extended to all patients • Requirement to review all relevant prior patient encounters added to clinical staff contracts • Working to implement a clinical system alert for children with sickle cell disease	Policy/process change Clinical system alert	No response to FOI request within the statutory period
None other than referencing existing policy programmes and initiatives	N/A	N/A
N/A	N/A	N/A
• Letter to all local GPs (via Local Medical Committee) reinforcing PPV enhanced-service responsibilities and vaccine-shortage escalation process • Serious Incident review/root cause analysis into GP practice's failure to act on 4 hospital letters requesting pneumococcal (Pneumovax23) vaccination • Action plan implemented by GP surgery: dedicated immunisation clinics, audit of electronic recording of hospital-letter actions • Confirmed with manufacturer/Public Health England that vaccine had in fact been available (no true supply shortage) - learning shared nationally to avoid confusion over vaccine naming • NHS England Performance Advisory Group convened; regulatory/capability process regarding the GP underway	Serious incident investigation Practice-level process change National communication to GPs	No response to FOI request within the statutory period
N/A - but some actions mentioned in NHS England response	N/A	N/A
• Continue to file/flag Individualised Care Plan (ICP) in patient record; hard copy of ICP now also filed at front of paper record, kept current by Haemoglobinopathy (HBO) Clinical Nurse Specialist (CNS) • New Standard Operating Procedure introduced for managing ICPs • Daily 7-day-a-week MDT board round on Haematology wards reviewing all new admissions and ICPs • ICP written for any new sickle cell disease patient without one, following board round • ICP reviewed and updated with patient at discharge • Regular audit of ICP availability commenced; results to be shared with Coroner by Sept 2024 • Sickle cell disease 'action card' developed for staff; ICP-focused training delivered to Haematology and Emergency Department staff (50 trained, 33 more planned) • New 'Connect' Electronic Patient Record (from Oct 2024) to record ICP with pop-out alert and direct link when a patient's record is opened	Standard Operating Procedure/process change Staff training IT/EPR system change Audit	No response to FOI request within the statutory period

Table 3: theme matrix for qualitative analysis of PFD reports relating to the deaths of people living with sickle cell, 2013-2026.

Name	Year issued	Substandard medical care across care settings	Lack of joined-up care	Lack of awareness	Negative attitudes towards people living with sickle cell	Lack of resources	Inadequate incident reporting, investigation and organisational learning
Emmanuel Akinmuyiwa	2014	✓	✓	✓		✓	
Akua Anokye-Boateng	2014		✓	✓			
Wayne Bayley*	2024	✓	✓	✓	✓✓		✓
Kamil Iddrisu & Youngson Nkhoma†	2019			✓✓			
Youngson Nkhoma†	2022	✓	✓	✓	✓✓		✓
Kingsley Imafidon	2024	✓	✓				
Urielle Kuyenga	2025		✓	✓			
Dave Onawelo	2024	✓		✓	✓	✓✓	
Johan Pambou	2017		✓			✓✓	
Darnell Smith	2024	✓	✓				
		6/10	8/10	7/10	3/10	3/10	2/10

✓ = theme stated by the coroner.
✓✓ = theme inferred by the reviewer.

* In the case of Wayne Bayley, thematic analysis was also performed on the report from the Prisons & Probation Ombudsman independent investigation.

† Kamil Iddrisu and Youngson Nkhoma were the subjects of a joint PFD report issued in 2019. A further PFD report relating only to Youngson Nkhoma was issued in 2022; however, this report still mentions the death of Kamil Iddrisu as relevant context.

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