North Middlesex University Hospital NHS Trust

North Middlesex University Hospital

Inspection report

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Ratings

Overall rating for this service	Inspected but not rated
Are services safe?	**Inspected but not rated**
Are services effective?	**Inspected but not rated**
Are services caring?	**Inspected but not rated**
Are services responsive to people's needs?	**Inspected but not rated**
Are services well-led?	**Inspected but not rated**

Our findings

Overall summary of services at North Middlesex University Hospital

Inspected but not rated

We carried out this unannounced focused inspection because we had concerns about the sickle cell services following a serious incident and because we received information giving us concerns about the safety and quality of care. This was a focused inspection, focusing on the quality of services delivered to patients with Sickle Cell Disease (SCD). Although we inspected all five key domains in relation to the services provided to patients with SCD (safe, effective, caring, responsive and well-led), we did not inspect any other aspects of the core service of Medical Care.

We have not rated this report because our inspection of the sickle cell pathway covered a number of core services within the trust and also sickle cell care is a small part of the medical care core service.

See the medical care section for what we found.

How we carried out the inspection

During the inspection we spoke with eight patients, 38 members of staff and reviewed six patient records. We visited the emergency department, acute medical unit, T4 ward and the haematology day unit. We spoke with different staff groups from different grades including: doctors, nurses, administration staff, managers, divisional leadership team and executive team. During our visit we looked at care pathways, reviewed records, inspecting the places where people were cared for, looking at documents and policies.

You can find further information about how we carry out our inspections on our website: https://www.cqc.org.uk/what-we-do/how-we-do-our-job/what-we-do-inspection.

Medical care (including older people's care)

Inspected but not rated

We inspected but did not rate. Following is an overall summary of our findings:

- We found the service had not always been given the attention required. Staffing, training and equipment were not always sufficient. Despite serving one of the larger populations of patients with red blood cell disorders such as sickle cell disease and thalassaemia it was a marginalised service with limited support from the division and the trust board.
- The service was mainly reactive, staff did not have the capacity nor support from their medical division to actively improve and develop it. There were no effective internal governance arrangements. Few meetings were happening where staff discussed patient outcomes, audits, risks, complaints and other performance indicators.
- The pace of improvement was slow and indicated the service was not always prioritised by the trust even in response to a serious incident of avoidable death. Some learnings from this incident were still not addressed or well embedded. While the service faced additional challenges during COVID-19 pandemic restrictions, which caused delays in some of the planned improvements, there was no assessment to establish which improvements the service could and could not deliver due to the restrictions.
- The trust struggled to identify a lead for the service following the departure of the red cell lead consultant. We acknowledge there is a national shortage of red cell consultants and we saw the trust's efforts to recruit a consultant before the post became vacant. The trust explored some alternative solutions in the face of these challenges to ensure appropriate cover was in place before the lead consultant had left however with limited success.
- The trust did not engage well with their local community to understand the needs of people who live with sickle cell disease and their relatives.
- The service focused too narrowly on the physical health of patients and there was limited support for their psychological and psychosocial needs. The service did not have access to allied health professionals such as dieticians, physiotherapists, or occupational health practitioners to holistically assess and support patients' complex needs.
- Pain management of people with sickle cell disease was suboptimal. Audit data shows the emergency department breached the NICE guideline (*NICE guideline CG143: Sickle cell disease: managing acute painful episodes in hospital*) in 82% of cases.

However:

- The service issued the first copy of sickle cell and thalassaemia patient's newsletter to inform patients about key changes and developments. The service planned to produce three newsletters per year.
- The red cell staff working within the sickle cell service were committed and caring professionals.
- The service introduced an electronic flagging system to alert the haematology team when patients with sickle cell disease were admitted. Staff wanted to develop this further to be able to track patient's journey through the hospital.
- The service developed and was in the process of rolling out a 'sickle 6' carry card and a sickle cell disease alert sticker for inpatient notes to help the non-haematology teams care for patients with the disorder.

Medical care (including older people's care)

Is the service safe?

Inspected but not rated

Mandatory Training

The service provided mandatory training in key skills to all staff and made sure everyone completed it.

Staff received and kept up-to-date with their mandatory training. Overall, the service met the trust target of 90% for the mandatory training completion rates. Mandatory training included 13 topics and the lowest completion rate was for Safeguarding Adult level 2 training with 82% completion rate.

Cleanliness, infection control and hygiene

The service controlled infection risk well. Staff used equipment and control measures to protect patients, themselves, and others from infection. They kept equipment and the premises visibly clean.

The areas we visited were clean and had suitable furnishings which were clean and well-maintained. Staff followed infection control principles including the use of personal protective equipment (PPE). Staff labelled equipment to show when it was last cleaned.

Environment and equipment

The design and use of facilities, premises, and equipment were not always adequate.

Staff tried to allocate patients with sickle cell disease (SCD) to T4 ward which was a short stay frailty ward with seven beds intended for patients with SCD. The trust told us when possible patients were allocated to a bay (or two when needed - male and female). However, staff on the ward told us this did not happen as this was not practical.

Staff told us about difficulties in obtaining equipment needed to care for their patients. The service had one automated blood exchange machine and access to another machine that belonged to the paediatric department. The haematology day unit relied on the paediatric machine to carry out automated exchange blood transfusions and had to wait for the machine to become available, which at times delayed the patients' treatment.

We noted that various specialist equipment used by the service that was fundraised by patients or donated by a charity, for example, one of the automated blood exchange machines, an Airglove machine (used to enable easier venous access) or a recliner chair. This shows a strong community spirit.

The service did not have patient-controlled analgesia (PCA) machines available to their patients. PCA is a method of pain control that gives patients the power to control their pain and is standard equipment used by specialist sickle cell services. Before the COVID-19 pandemic restrictions, there was a meeting where staff discussed the rollout of the PCA pumps. However, the COVID-19 pandemic restrictions impacted upon clinical priorities within the trust and consequently delayed this rollout. Following the inspection, the trust confirmed that priority had since been given to the implementation of PCA pump training and the availability of pumps had been added to the risk register.

Medical care (including older people's care)

We could not assess if patients could reach the call bells and staff responded quickly when called as the service did not carry out regular audits. In the last 12 months, the proximity of call bells to patients was assessed once, in May 2021, during a broader review of T4 ward. The assessment showed that all patients in the ward had call bells close to them and no concerns were noted. Following the inspection, the trust stated they would consider inclusion of call bell response times in future ward accreditation audits.

Assessing and responding to patient risk

Staff did not always take appropriate action to addressed removed or minimised risks.

Since patients with SCD who undergo a procedure have an increased risk of perioperative complications, the haematology team requires other specialities to inform them about any surgeries as soon as the date is decided. Patients with SCD must be managed jointly by a surgeon, anaesthetist, and haematologist to plan for an automated red blood cell exchange procedure. The trust had a system for flagging patients with SCD who were already in the hospital, however, staff told us they were not informed by other specialities as soon as the procedure was scheduled to allow appropriate planning. Staff told us that at times the haematology team was only informed about patients once they were in the operating theatre or after the surgery. The trust was unable to tell us how many patient procedures had to be rescheduled due to the red cell team not being informed. Lack of communication from other specialities was one of the issues identified for improvement following the incident of avoidable harm.

In response to one of the findings from the incident of avoidable death, the trust decided to allocate patients with SCD to T4 ward. Staff told us an audit of the compliance with this standard showed there was a significant number of patients who still end up on a different ward. This was a concern as the skill mix on other wards was not at the same level as on T4. We requested the audit data however the trust did not provide it. To ensure patients' safety, staff told us doctors prioritised the review of the outlying patients. The red cell outreach team also provide oversight and additional specialist support. Staff were hopeful that a sickle cell awareness day that took place in June 2021 would improve compliance with the patient allocation.

Most staff we spoke with knew about patients' individualised care plans and how to access them. However, staff told us not everyone in the emergency department had log in details to access the electronic system where the plans were stored. Following the inspection, the trust acknowledged that there might be a need for refreshed education to ensure staff knew how to access the plans.

The individualised care plans should be reviewed and updated at least annually. However, staff told us this did not always happen due to pressures on the service. During the inspection we reviewed six patient care notes, one record was missing the individualised care plan and the other had a care plan that was last reviewed in 2016.

Staff recognised that the nationally recognised tool to identify deteriorating patients (National Early Warning Score NEWS) was not as effective in monitoring patients with SCD. To enhance and supplement the process they developed an additional tool called 'sickle cell 6'. Sickle Cell 6 was due to be rolled out.

Staff knew who to contact if they had concerns. We saw that staff appropriately escalated patients.

Nurse staffing

The service had enough nursing and support staff; the levels of qualifications, skills, training and experience was variable.

Medical care (including older people's care)

The mix of qualifications, skills, training and experience in relation to SCD varied between different areas of the hospital depending on which speciality staff were working in. Staff on T4 ward (where patients with SCD were most commonly treated) we spoke with displayed good knowledge of SCD.

The vacancy rates for the medical division were usually between 4-7%. The service had low turnover rates. The service had low sickness rates, usually between 3-4%.

Medical staffing

At the time of the inspection, the lead red cell haematologist for the service was about to depart due to resignation. Inpatients were reviewed by haematology and general medicine doctors

The service had one red cell consultant haematologist however they did not work full time and split their role between adults and children. There was no other consultant whose speciality was sickle cell and thalassemia since the lead consultant left the trust the day after our inspection visit. The trust told that from early September a locum doctor would cover one outpatients clinic a week to help with the workload. Because of that, there was no red cell consultant to attend ward rounds or who covered an out of hours (OOH) rota. Inpatients were reviewed by haematology consultants and medical consultants. Consultant ward rounds were Mondays and Thursdays. Junior haematology doctors reviewed patients on Tuesdays, Wednesdays, Fridays, and weekends and would escalate any concerns to consultants.

While the acute medical team covered the OOH rota, staff said that their knowledge was broader, and they did not always have the specialist sickle cell (SC) experience. There was an on-call consultant haematologist 24/7 and at the weekends a haematology registrar did ward rounds, with a haematology consultant reviewing new and sick patients on Sundays. It was not clear who was taking over the oversight of the service, including some of the outreach clinics, following the departure of the lead consultant. The trust indicated a few individuals who were taking over the extra tasks however staff told us they had little capacity to take on the additional responsibilities.

Records

Staff used a mixture of electronic and paper records. These fragmented records made it more challenging for staff to track patient's medical history.

Staff used a mixture of paper and electronic records. For example, the emergency department used a paper-based system, while on the wards the system was electronic. This did not allow good visibility of patient information to, for example, assess the trajectory of a patient's condition and identify potential signs of deterioration. This also meant that staff did not have immediate access to patients' complete medical records from their previous hospital visit. As mitigation a process has been implemented to support patient transfers to locations that were not yet live with the electronic medical and nursing notes / assessments. The green sticker provided an indicator to all clinical staff in non-digital areas to review the patient's electronic note.

Incidents

Staff did not always recognise and reported incidents and near misses. L**essons learned were not regularly shared with the whole team and the wider service.**

The review along with what staff told us shows that incidents in relation to sickle cell patients were underreported. There were 24 incidents reported by staff in the 12 months prior to the inspection. The most common incident type (nine incidents) related to medicines: unavailable stock leading to delays or medicines errors; five incidents related to staff not following the agreed protocols related to escalation, care plans or allocation to T4 ward. However, during the

inspection staff told us about other issues which were not reported, such as delays in administering analgesia due to work pressures, delays in clinics due to availability of the equipment, unlabelled blood samples, haematology team not being notified about elective procedures or staff demonstrating negative attitude towards patients. There were limited learning opportunities. Staff did not meet to discuss the feedback and look at improvements to patient care.

Is the service effective?

Inspected but not rated

Evidence-based care and treatment

The service did not always monitor compliance and effectiveness to ensure care and treatment provided were based on national guidance and evidence-based practice. Managers infrequently checked to make sure staff followed guidance.

The trust guideline on clinical care of adults with SCD was very comprehensive and in line with the national standards. However, the care and treatment provided by the service to patients with sickle cell disease (SCD) were not consistent with the principles of holistic support. The service did not consider the wider determinants of health and psychosocial factors when assessing patients.

The performance against national standards was variable. For example, 'annual review completion' rates were among the best 1% nationally in 2019/20 with 94.6% of reviews completed. However, in 'A&E: analgesia within 30 minutes' standard the service was in the worse 1% performing services in 2019/20. The service was ranked average for 'timely iron overload monitoring' and 'iron overload targets achieved' standards. Their performance was ranked in the 25% worst services for Trans Cranial Doppler (TCD) screening with 74.5% compliance.

In 2019 the service carried out a desktop quality standard self-assessment. The review is carried out every three years and is part of a clinical peer review programme for haemoglobinopathies. On this occasion 17 out of 51 standards were reviewed. The range of compliance fell between 7% and 100%, with the overall quality standards score of 88%.

The service did not regularly monitor if staff followed up-to-date policies to plan and deliver high-quality care according to best practice and national guidance. In one of the areas we visited, staff had a folder with information, policies and guidance related to SCD however some information was outdated. We saw a summary of an audit related to staff adherence with the sickle cell management guideline on observations and investigations. The data showed that 100% of admitted patients had delays in observations. Of 16 patients whose set of observations had critical values and increased frequency of observations was required, the mandated interval was achieved in only two cases.

At handover meetings, staff did not routinely refer to the psychological and emotional needs of patients, their relatives and carers.

Nutrition and hydration

Patients were not reviewed by dieticians or speech and language therapists to meet their needs and improve their health.

Sickle cell patients were not assessed or referred to dieticians to comprehensively assess their nutritional needs. The service did not offer nutritional support and advice on healthy eating. Specialist support from staff such as a speech and language therapist was not available.

Pain relief

Patients frequently experienced delays in receiving pain relief.

Pain management of patients with SCD was suboptimal. According to NICE (*NICE guideline CG143*) patients presenting as a medical emergency with an acute painful episode should be offered appropriate analgesia within 30 minutes of presentation to the emergency department. Staff told us about significant delays in administering first and second doses of analgesia in the emergency department where patients with SCD were not prioritised. The A&E pain audit for the period between May to October 2020 demonstrates that the department was consistently breaching the 30 minutes to first dose standard. Data shows the department breached the NICE guideline in 82% of cases. The audit data only comments that the time was greater than 40 minutes therefore we were not able to assess how significant the delays were. Of the six patient notes we reviewed, all patients received analgesia with delays. This meant patients were left in severe pain leading to poor experience.

No pain audits were carried out on the wards. While staff told us pain management was better on T4 ward, there was no data to confirm that. Staff on the ward told us the delays in administering analgesia was often due to workload or because they struggled to find a key for the drugs cupboard. The key was shared between staff and it was not always easy to identify the last person that used it. Once the key was found staff had to find a staff member who was available to sign for the analgesia which led to further delays.

Staff told us the service had a ring-fenced supply of injectable opioids for patients with SCD to ensure these were always available. However, we saw incidents where the medication was not readily available and staff had to request it from other areas of the hospital which caused unnecessary delay.

The service introduced disposable heat pads to use alongside analgesia to ease patients' pain during the sickle cell crisis.

Competent staff

Not all staff were fully competent for their roles. Managers did not appraise staff's work performance and did not hold regular supervision meetings with them to provide support and development opportunities.

The service did not have an adequate skill mix within the team. We were told that taking blood and/or placing a cannula can be challenging in patients with a red cell disorder and therefore exceptional cannulation skills were vital. However, three out of eight haematology nurses did not have adequate intravenous cannulation skills. Also, two out of eight nurses were not trained in delivering automated blood exchanges and five out of eight nurses were not trained in manual blood exchange. There were two clinical nurse specialists (CNS) in post, with different clinical skills. One had expertise in acute care whilst the other was a community / genetic counselling expert.

Managers failed to support staff to develop through yearly, constructive appraisals of their work. Only five out of 13 nursing staff of the red cell team had completed appraisals. Following the inspection, the trust provided an action plan to address this gap.

In 2019 nursing staff on T4 ward received comprehensive training on sickle cell and thalassemia. It was a month-long program with a final exam. Staff on T4 ward displayed good knowledge and experience of caring for patients with SCD.

However, most of the new nursing staff on T4 did not have the opportunity to complete the SCD competency programme. During COVID-19 pandemic restrictions, T4 ward was principally used as a general medical ward and the priority was to ensure there were sufficient numbers of nursing staff with the right skills to care for these patients. Following the inspection, the trust said the SCD training programme had since been reprioritised for the new staff in T4 ward. There was no ongoing training program for nursing staff on other hospital wards and the knowledge of SCD was not part of their induction programme. The trust data showed that 29.1% of staff on the acute medical unit (AMU), emergency department (ED) and T4 have received training on SCD.

The trust told us training took place in the ED every week, on a Thursday. However, most staff in the ED we spoke with could not remember the last time they received training on SCD. Staff told us this was due to work pressures in the department. In the 12 months prior to the inspection, training sessions for junior doctors that covered SCD happened on two occasions, in November 2020 and July 2021. The next session was planned for October 2021. Training in other areas of the hospital happened ad hoc. The trust told us the training provision was impacted by the COVID-19 pandemic restrictions. No training sessions were happening in the AMU at the time of the inspection. The trust told us that in the last year, two multi-professional education sessions specifically focusing on SCD happened in the ED. Most staff we spoke with could not recall the last time they received training on SCD. Two clinicians we spoke with told us they did not deal with patients with SCD despite working in the area regularly attended by these patients.

Since the junior doctors rotated each year, their training took place each year during their induction. At the time of the inspection, a new cohort of junior doctors started their placements however the date of the induction into SCD was still not scheduled.

In June 2021 the red cell team organised a sickle cell awareness event available to all staff. The trust told us this was well attended with approximately 200 staff joining various lectures throughout the day. There was a good attendance from T4 ward with nine staff members from different staff groups attending the event including a housekeeper, trainee nurse associate, ward manager, staff nurses, ward clerks and deputy ward managers.

Non-red cell staff were very positive about the red cell team. They said they were very knowledgeable, helpful and available to advise and assist.

Multidisciplinary working

Doctors, nurses and other healthcare professionals worked together as a team to benefit patients. However, allied health professionals were not involved in the multidisciplinary care.

The red call team attended regular internal and external multidisciplinary (MDT) meetings to discuss patients that were under their care. For example, they attended a monthly joined MDT meeting with another trust to discuss complex cases. The team held regular internal MDT meetings such as a weekly red cell MDT meeting where staff discussed individualised patient cases. The meetings were attended by a consultant, clinical nurse specialist (CNS), blood transfusion practitioner, psychologist, data manager and occasionally the service manager. There was a weekly interventional radiology MDT meeting attended by consultants, junior doctors, CNS, a radiologist and a microbiologist. However, allied health professionals (AHPs) such as a physiotherapist, occupational health, dietitian or social worker were not involved in these meetings.

The MDT working was less effective when patients were under the care of other specialities, for example, surgery or gastroenterology. Staff told us they did not jointly plan care for patients with SCD. Furthermore, the red cell team was not always notified in advance that a patient was undergoing a procedure. This issue was not addressed despite being identified during the serious incident of avoidable death that happened in 2019.

The service had several clinics to support patients with SCD. For example, genetic counselling, a post-discharge clinic where patients were contacted after their discharge to discuss any issues, a hydroxycarbamide clinic, or a chronic pain management clinic. The pain management clinic was run by a consultant and a psychologist with no input from AHPs or CNS who could not attend due to the workload. As such, the clinics could not always provide the most optimal holistic care to patients with complex pain needs.

Health promotion

There was limited evidence the service supported patients with practical support and advice to lead healthier lives.

While the divisional leads said the service tried to promote community wellness, we saw no evidence of that. The trust said annual review meetings included assessment of lifestyle behaviours and were an opportunity to provide advice or referrals for further support. The trust shared with us a leaflet that included various information about living well with sickle cell, however, it was unclear how available it was. Patients we spoke to said they have not been advised on healthy living or offered any written material. No other relevant information about providing support for individual needs specific to SCD was available.

Is the service caring?

Inspected but not rated

Compassionate care

While sickle cell staff demonstrated compassion and kindness, not all non-haematology staff treated patients with compassion and kindness and took account of their individual needs.

Sickle cell staff showed an encouraging, sensitive and supportive attitude to people with SCD. They gave us examples when they challenged other staff who displayed disrespectful attitude towards patients. Staff understood the emotional and social impact that SCD had on people's wellbeing and on those close to them. However, the needs of patients with SCD were not always well understood by non-haematology staff. We saw and heard from staff and patients that the SC-related stigma was still present amongst some staff who were infrequently caring for patients with SCD. The stigma can have a significant impact on patients, by hindering their physiological and psychological wellbeing, as well as having a detrimental effect on care-seeking behaviours and the patient-provider relationship. Staff told us that some staff did not take the disease seriously and some staff developed an opinion that patients with SCD were "difficult" or "problematic". One clinician stated that some patients try to "manipulate" staff to get stronger analgesia, or that patients do not want to engage with them and "just want to get drugs". A patient told us staff made her feel like she was a drug addict. They were suffering from severe pain and they felt ignored. Another patient mentioned that triage staff in the emergency department did not listen to her despite being in excruciating pain.

Emotional support

There was limited evidence non-haematology staff provided emotional support to patients, families and carers to minimise their distress.

There was limited evidence patients' emotional wellbeing was part of their regular reviews. Most patients we spoke with said there was no mental health support available to them. A patient who had their annual review six months before the inspection told us the reviews were never about their psychological wellbeing, only focused on physical needs. Two other patients said the reviews were never about their mental wellbeing and that no support was offered.

Medical care (including older people's care)

Non-haematology staff did not always demonstrate empathy and support for patients who became distressed. The presence of the SC-related stigma amongst some staff indicates that staff did not always understood the emotional and social impact their treatment and condition had on their wellbeing.

Following the inspection, the trust stated they were working to improve holistic multi-disciplinary working within the annual review process. The need to engage with the stakeholders and service users to improve how the service met the needs of the patients and their families was a priority for the leadership team.

Is the service responsive?

Inspected but not rated

Service planning and delivery to meet the needs of the local people

The service did not plan and provide care in a way that met the needs of local people and the communities served.

There was limited evidence to show the service was developed to meet the needs of their local populations. The service did not assess the changing needs of the local population therefore managers could not plan and organise the services to meet these needs.

Facilities and premises were not always appropriate for the services being delivered. The leadership team told us that the reason behind allocating T4 ward was a pragmatic one and was due to the ward being one of the larger wards. T4 ward was a short stay frailty ward that looked after elderly patients who often suffered from dementia or confusion. While the trust told us two bays and two side rooms were intended for patients with SCD in reality patients were spread across all bays and mixed with other patients. The environment was not always conducive to patients' well-being and comfort. Patients told us about being unable to sleep due to noise and wandering, confused patients. One patient said T4 was "not the right environment" for them and asked if there was a sickle cell ward within the hospital. Another patient said that the two patient groups should not be mixed and that they were not comfortable most of the nights. The environment was not appropriate for patients with additional needs such as autism or learning difficulties.

While the service had a psychologist with specialist expertise in sickle cell and thalassemia, it was one person and the role was not filled in if they were on leave.

Staff told us the DNA rates (did not attend) were high in the outpatients clinics. Between April 2020 and August 2021, the DNA rate was 18%. The trust took some action to reduce the rates however review of the data shows this had no impact, in fact the rates had gradually increased over the months.

The service did not know what the DNA rates were for missed blood transfusion appointments due to a data validation error. This is a significant metric that the service should monitor as high DNA rates lead to blood units being wasted; it is costly in terms of money and time. The trust informed us that work was underway to improve data validation process and the plan was to audit this metric in the next six months.

The trust had a dedicated sickle cell and thalassemia webpage so that patients could find further information about the services provided.

Medical care (including older people's care)

Access and flow

The arrangements to admit patients into the most appropriate ward were not always followed.

Staff told us patients with SCD were regularly allocated to other wards than the dedicated T4 ward. This meant that patients were looked after by staff who were not always familiar with their care needs. Staff told us there was a lack of support from the division to ensure patients were allocated to the most appropriate ward. The site managers did not always prioritise the allocation of patients with SCD to T4 ward. We asked the trust for an audit on the compliance with the allocation however this was not provided. However, managers made sure they had arrangements for medical staff to review any patients with SCD on other wards.

Learning from complaints and concerns

The service did not effectively capture feedback and encourage people to raise concerns about care received.

There was limited evidence the service used concerns and complaints as an opportunity to learn and drive improvement. Senior staff struggled to give examples of how they used patient feedback to improve the daily practice. When asked about three examples, only one out of three examples demonstrated improvement to the service in relation to SCD.

Staff told us feedback from complaints with staff happened on an ad hoc basis. In the 12 months prior to the inspection, the trust received five formal complaints from patients with SCD. However, during our inspection visit, all eight patients we spoke with gave us negative feedback about certain aspects of their care and treatment or shared their concerns. Therefore, we were not confident that the service had a good system to capture feedback and complaints from patients in order to drive improvement and learn.

Is the service well-led?

Inspected but not rated

Leadership

The service did not have a leadership team that had the capacity and could effectively run the service. The divisional leadership team did not always understand and manage the priorities and issues the service faced. Not all leaders were visible and approachable in the service for patients and staff.

The red cell team was meant to be led by a consultant haematologist specialising in haemoglobin disorders; however, following the departure of the red cell lead consultant the day after the inspection, this post became vacant. The service was overseen by the divisional managers including the clinical director, the service manager and the divisional director of nursing. The associate director of nursing was also directly involved in overseeing the service.

The service had no leadership strategy or development programme, which would include succession planning. At the time of the inspection, the lead consultant for the red cell team was leaving and there was no clear plan on how the service would be run. The red cell team foresaw the issues with recruiting for the consultant post and we saw from the meeting minutes they suggested alternative solutions. However, these were not acted on by the leadership team in a timely fashion.

In November 2020, the red cell team identified a need for a nurse consultant post however, due to Covid-19 pandemic restrictions, it was not until April 2021 the trust approved the post for a nurse consultant for sickle cell. The plan was to advertise the role in May 2021. At the time of the inspection, this was still outstanding, and the advert had not been published.

The medical division leadership team did not always display a good knowledge of the sickle cell service. For example, we were told that it was very rare that patients with sickle cell disease (SCD) stayed in the Acute Medical Unit (AMU). However, a review of the records showed that every week at least 1-3 patients were admitted to the AMU prior to being moved into a ward. This demonstrated the leads did not have a good awareness of the patients' journey. Also, while the divisional leads told us there was an "excellent" standard operating procedure pathway for patients who start their journey in the emergency department and were later moved to general medical wards, we did not see it in practice. Patients often did not receive their analgesia on time, were often moved to the AMU before being transferred to a ward and were not always transferred to the ward dedicated to patients with SCD. The trust told us there was ongoing training for new staff on T4 ward and the emergency department, however, this had not happened due to limited resources and workload.

In response to the serious incident of avoidable death that happened in 2019, the trust told us they strengthen divisional and sub-divisional level leadership, however, there was little evidence this translated to improvements within the red cell services. The trust told they had strengthened the leadership but, staff felt no one championed their service. While the trust said the leadership team was visible throughout the division, staff said that most members of the leadership team were not visible and approachable.

The executive team told us there was very good board scrutiny of the SCD work with a clear line of sight from the board on what was happening however we saw that despite this oversite the pace of improvement was still slow. In December 2018 the board was told about a need for closer working with community services. The board noted that "There was a need to involve patients in the design and delivery of the service." This was never effectively addressed. We were told about some ad hoc engagement with individuals and small groups of patients, but these were not formally and effectively embedded. While the sickle cell service was discussed at the board on different occasions in the last two years, for example, in relation to a wider controlled drugs audit, or in response to a question from the public, it was not until July 2021 that the board was presented with an overview of the service and the non-executive directors had the opportunity to scrutinise the service. The presentation had been made in response to the learnings from an incident of avoidable death and a need to improve the service, however this avoidable death happened two and a half years earlier. While some improvements to the service were made, there was limited assurance these were well embedded, several actions were still outstanding or never addressed.

Vision and Strategy

The service did not have a clear long-term vision for what it wanted to achieve, there was no comprehensive operational plan supported by staff and patient. Staff and service users were not involved in service planning and the pace of change was slow.

The trust did not have a vision for the service. The leadership team told us they were in the process of developing the vision and the strategy however the pace of this work was slow. Senior staff told us about ambitions for the service however it was unclear how and by whom these were formulated. Staff involved in the care of patients with SCD were not aware of these plans and were not involved in the development of the vision and strategy.

While senior leaders told us, they wanted the process to be led by the service users, no engagement sessions were organised at the time of the inspection. However, the trust had begun an engagement with the national charity that supports and represents people with SCD and involved them in the initial discussions about the future of the service.

July 2021, the executive team and divisional leads carried out a 'deep dive' exercise to better understand the service. This was an initial review to understand the size of the service, operational and governance matters, strengths, weaknesses and risks aimed to help in developing the vision and strategy. This was led by the leadership team, and while the red cell team was asked to provide the data they were not involved in the analysis of their service. They also did not know the outcome of this exercise and how this was meant to develop and improve the service.

The red cell services had not been planned to meet the needs of the population to deliver good quality sustainable care. For example, the trust planned to move sickle cell patients from T4 ward to a different area of the hospital. The area was small and could hold four to five beds however, the hospital usually had significantly more sickle cell patients seven inpatients with SCD on T4 ward. According to the trust data the service had anything between eight to 15 inpatients on a given day. This meant that the plan would create numerous outliers and patients with SCD would be dispersed and admitted to various wards with limited expertise and knowledge of SCD.

We noted that the trust talked about the need to refurbish George Marsh centre (a separate site specialising in SCD) due to its poor condition for over a year however the progress of this work was slow. Following the inspection, the trust confirmed that capital funds to proceed with a full refurbishment of the George Marsh Centre were approved.

Culture

Staff did not always feel respected, supported and valued. Staff and teams were not always focused on the needs of patients receiving care.

We heard examples where staff expertise, knowledge, ideas and concerns were not always considered by the divisional team. Staff did not feel valued and were offered very limited or no opportunities for their career development.

Staff and teams did not always work collaboratively to resolve issues quickly and constructively. There was an ongoing issue with patients regularly not being allocated to the dedicated ward for patients with SCD, T4 ward. Since there was limited support from the site managers, staff found an alternative process to ensure patients with SCD were cared for on T4. This was a known issue to the divisional team, but no effort was made to address it. While this shows that staff tried their best for their patients, it also indicates poor culture and poor understanding and appreciation for the needs of patients with SCD amongst other teams.

The lack of awareness and sufficient education around sickle cell amongst staff who did not frequently care for patients with SCD meant that the stigma of SCD was still present. This was despite the trust serving one of the larger populations of people who live with SCD in the country. Staff told us the negative perception of patients with SCD was still present amongst some staff.

Governance

Leaders did not operate effective governance processes throughout the service. Staff at different levels did not have regular opportunities to meet, discuss and learn from the performance of the service.

The service did not have the appropriate governance arrangements to support improvements of service. While staff were committed and enthusiastic about their work, their workload only allowed them to focus on patient care and urgent work with limited input into developing and improving the service.

The trust told us the governance of the red cell service was covered under the haematology service governance meetings however no meeting had taken place since December 2019 due to the COVID-19 pandemic restrictions. The trust said the team had been holding their operational meetings in lieu of the governance meetings. These were well attended, bimonthly meetings however a review of the meeting minutes showed that staff discussed operational matters. There was no discussion about risks, audits, outcomes, incidents, complaints and any other metrics to understand their service, learn and improve. Senior staff told us that if needed issues related to the service would be taken to the monthly divisional governance meeting however this was very rare. A review of the divisional governance meeting minutes showed that between July 2020 and July 2021 the red cell services were not discussed during the meetings.

The service had limited resources to undertake local quality audits therefore prioritised the national audits. Compliance with several protocols and changes proposed as a result of learning from an incident of avoidable harm were not audited to ensure behaviours had changed. There was no audit to assess compliance with individualised care plans, allocation to T4 ward, or pain audit on the wards. Audits happened ad hoc and usually in response to concerns or incidents. The trust told us that compliance with NEWS and associated issues were monitored at a monthly deteriorating patient forum. However, this was a newly established meeting which commenced in March 2021 and no further meetings had happened since. Trust told us that audits concerning SCD, other than the pain audit in the emergency department, were not completed due to COVID-19 pandemic restrictions. However, there was no evidence these were carried out before the pandemic. There was no plan to commence them.

Management of risk, issues and performance

Performance and improvement plans were not always effectively managed. Not all risks identified by staff were on the risk register.

The pace at which changes and improvements to the service were introduced indicates that the trust did not prioritise the service despite senior leaders stating they were the fifth largest sickle cell centre in England and acknowledging this disease disproportionately impacted some of their local communities. Covid-19 pandemic restrictions added to the existing delays. Review of meeting minutes show that despite red cell staff attempts to improve or change the service things were not being progressed due to bureaucracy, slow response or not being listened to. We saw examples of emails not being responded to, or recruitment not progressing despite months of assurance these would be actioned.

Around May 2021, the service developed a structured improvement plan that was led by an executive director. Despite the plan being very detailed it was not always clear how the team measured and assessed the impact of the changes. During the inspection, we found several issues in the areas the plan indicated were addressed. For example, one of the tasks was for weekly sickle cell awareness training to be developed for the emergency department, however, staff told us this often did not take place. Another task was to updated sickle cell disease guidelines, however, compliance with the guidelines was not monitored. A patient feedback form for patients with SDC was developed but no feedback was collected.

The red cell services had two risks on the haematology services risk register. One related to the departure of the lead consultant and not having a sickle cell lead; the other related to an inadequate out of hours cover for the emergency red cell exchange blood transfusion. At the time of the inspection, the trust was in the process of introducing a nursing rota to cover the out of hours exchange blood transfusion service. However, the two risks did not reflect all the risks shared with us by the team. For example, staff told us that losing another staff member would be critical for the team. They also highlighted risks related to the move of the SC ward.

Medical care (including older people's care)

Information Management

The service did not collect reliable data and analyse it to understand performance, make decisions and improvements.

The service was very reactive, and staff did not have the capacity nor support from the division to collect and analyse data to understand their performance and improve the service.

The A&E pain audit carried out between May and October 2020 shows there was 30% of data missing within different areas of the data collected. This had an impact on the audit findings as the extent of the problem could not be fully captured and assessed by the team.

A few months before the inspection the trust introduced an electronic patient tracking system so that the haematology team could easily identify the location of patients with SCD in the hospital. However, staff told us they were unable to track patients' journey through the hospital as the system only provided their current location. Also, it did not produce a list of all the patients and their current location, instead, staff had to manually open each patient record and extract this information. Staff told us they highlighted the issues with the relevant staff, but it was unclear when the system was going to be modified.

Engagement

There was limited evidence leaders and staff actively and regularly engaged with patients, staff, equality groups, the public and local organisations to plan and manage services. There was some recent evidence of collaboration with partner organisations to help improve services for patients.

The trust told us there was an ongoing engagement with the local community about how they can make the service better. However, we found there was poor engagement with patients and their relatives as well as the local organisations to plan and manage the service. We were made aware of one recent collaborative meeting between the trust and a SC organisation that aimed to help improve the service for patients. No regular engagement meetings with patients or local organisations were happening within the trust. Senior leaders could not provide any meaningful examples where service was improved as a result of patients' feedback.

Leaders did not actively and openly involve staff in their plans for the service. Many decisions were made at the divisional or trust level without consulting the team. Staff did not always know about the short-term and long-term plans for the service. Since the lead red cell haematologist for the service was about to depart due to resignation the trust told us that a locum consultant had been appointed to fill the role however, staff expressed feelings of uncertainty about the future of the service. Staff were not sure who was going to take over the lead's responsibilities and workload.

We noted there were early efforts to engage and reach out to the community. At the time of the inspection, the red cell team was in the process of sending feedback forms to the patients to seek their views about the service. It was the first time this was done by the service. In June 2021, the service issued the first sickle cell and thalassaemia patients' newsletter. The service planned to produce three newsletters each year, providing key information about the service, outlining any developments and changes.

Four months before the inspection, the trust's medical director wrote about sickle cell disease and the services they provided on four occasions through the weekly medical director's update newsletter in an effort to raise staff awareness of the disease and the profile of the service.

Medical care (including older people's care)

Learning, continuous improvement and innovation

There was limited evidence of continuous learning and improvement. There was limited evidence of innovation and participation in research.

Learning from an external review was not effectively acted on to drive improvement. An action plan against the external review from 2016 showed that several actions were still outstanding at the time of the inspection. Some of the concerns from the review were still identified during this inspection; for example, limited access to psychological support, the workload of the red cell team, long waiting times for analgesia, lack of a dedicated social worker or housing support, or the lack of audits.

At the time of the inspection, at least three clinical trials were happening in the UK that were recruiting patients with sickle cell disease. In the last three years, the trust referred four patients for clinical trials. There were limited opportunities for clinical research happening at the trust.

The trust approached Health Education England to discuss the newly developed national sickle cell disease competencies and expressed their desire to be a pilot site for implementation of these competencies.

The trust engaged with a patron of a sickle cell charity who provided advice and support to the senior nursing leadership team about SCD. The first meeting took place in May 2021 with two further meetings planned sometime in the future.

In order to improve patient care in the emergency department, the red cell team developed stickers that were placed in patients notes to make them more identifiable and remind staff they can deteriorate very quickly. The team also designed a ‘sickle 6’ carry cards to help non-haematology staff care for patients with SCD. The two ideas were in the process of being rolled out.

Areas for improvement

Action the trust MUST take is necessary to comply with its legal obligations. Action a trust SHOULD take is because it was not doing something required by a regulation but it would be disproportionate to find a breach of the regulation overall, to prevent it failing to comply with legal requirements in future, or to improve services.

Action the trust MUST take to improve:

- The trust must ensure all staff throughout the trust are competent for their roles in supporting SCD patients. (Regulation 12 Safe care and treatment)
- The trust must ensure the haematology team is informed about patients with SCD undergoing any procedures in a timely manner. (Regulation 12 Safe care and treatment)
- The trust must ensure that SCD patients receive personal care that meets their individual needs. The trust must ensure all staff have access to patients’ individualised care plans. (Regulation 9 Person centred care)
- The trust must ensure effective pain management and compliance with NICE guideline CG143. (Regulation 9 Person centred care)
- The trust must ensure appropriate governance arrangements for the service. (Regulation 17 Good governance)
- The trust must ensure staff comply with the national and local policies and guidance in relation to sickle cell disease. (Regulation 12 Safe care and treatment)

Medical care (including older people's care)

- The trust must ensure the service has equipment needed to deliver safe care and treatment. (Regulation 12 Safe care and treatment)
- The trust must ensure staff report incidents, any identified learning is shared and embedded. (Regulation 17 Good governance)
- The trust must ensure the service has a good system to capture feedback and complaints from patients in order to drive improvement and learn. (Regulation 17 Good governance)
- The trust must introduce a local audit programme for the service. (Regulation 17 Good governance)
- The trust must ensure there are robust arrangements for identifying, recording and managing risks, issues and mitigating actions. (Regulation 17 Good governance)

Action the trust SHOULD take to improve:

- The trust should consider appropriate arrangements for replacing the lead consultant to ensure continuity of effective management.
- The trust should ensure the service has a robust, realistic strategy for achieving the priorities and delivering good quality sustainable care. The trust should ensure the strategy is developed in collaboration with staff, people who use services, and external partners.
- The trust should ensure people who use services, those close to them and their representatives are actively engaged and involved in decision-making to shape services and culture.
- The trust should consider introducing patient-controlled analgesia (PCA) machines to improve patient experience.
- The trust should ensure seamless arrangements for staff on wards to administer controlled drugs.
- The trust should consider involving relevant allied health professionals in care of patients with sickle cell disease.
- The trust should ensure health promotion material was available and offered to patients.
- The trust should monitor and improve the DNA (did not attend) rates in the outpatients clinic.
- The trust should ensure positive culture within the service where staff feel supported, respected and valued.
- The trust should consider further developing the IT system to be able to track patients' journey through the hospital.

Our inspection team

The team that inspected the service comprised a CQC lead inspector, and a specialist advisor. The inspection team was overseen by Nicola Wise, Head of Hospital Inspection.

This section is primarily information for the provider

Requirement notices

Action we have told the provider to take

The table below shows the legal requirements that were not being met. The provider must send CQC a report that says what action they are going to take to meet these requirements.

Regulated activity	Regulation
Treatment of disease, disorder or injury	Regulation 12 HSCA (RA) Regulations 2014 Safe care and treatment

Regulated activity	Regulation
Treatment of disease, disorder or injury	Regulation 9 HSCA (RA) Regulations 2014 Person-centred care

Regulated activity	Regulation
Treatment of disease, disorder or injury	Regulation 17 HSCA (RA) Regulations 2014 Good governance