Public Health, Communities, & Public Safety

Sickle Cell Disorder profile

Part of the Suffolk Joint Strategic Needs Assessment (JSNA)

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SUFFOLK JSNA

Contents

AI: Some information in our Joint Strategic Needs Assessment (JSNA) products may have been summarised with the help of artificial intelligence tools. Everything is carefully checked by our team to make sure it's accurate.

Introduction

Sickle Cell Disorder (Sickle Cell) is a group of inherited blood disorders that affect the shape and function of red blood cells. People living with Sickle Cell can experience a wide range of health impacts, including chronic anaemia, acute pain episodes, and increased risk of serious complications affecting multiple organ systems. While it is a relatively rare condition in the overall population, it is more common among people from African, Caribbean, Middle Eastern, South Asian and Mediterranean backgrounds, including people with family origins in some other parts of Europe (such as France and Italy[1]).

In Suffolk, the number of people living with Sickle Cell is small (within a range of around 90-120 individuals) but important. The condition requires lifelong management, coordinated care, and responsive services that can meet both routine and urgent needs. As Suffolk's population continues to diversify, there is a clear need to understand the local profile of Sickle Cell, including who is affected, how needs present across the life course, and how well services are currently meeting those needs.

This Joint Strategic Needs Assessment (JSNA) profile brings together available evidence to provide an overview of Sickle Cell in Suffolk. It aims to:

- describe the local population affected by Sickle Cell
- identify key health and wellbeing needs
- highlight inequalities in access, experience, and outcomes
- support commissioners and providers to plan services that are equitable, responsive, and person-centred

Given the relatively small numbers involved, this profile also recognises the importance of qualitative insight and lived experience alongside quantitative data. Understanding how people navigate services, manage symptoms, and experience care in Suffolk is essential to building a system that is both clinically effective and compassionate.

Language used

This profile aims to use clear, person-centred and respectful language throughout, recognising that people are not defined by their condition. We prioritise terminology that reflects individuals' experiences and avoids stigma wherever possible. However, some clinical and data sources use established medical or technical terms that may not always align fully with person-centred language; where this occurs, we have retained necessary terminology for accuracy and clarity. We are committed to being inclusive and respectful, and we welcome feedback to help us continually improve how we communicate.

Whilst "Sickle Cell" is not an official clinical term, this profile generally uses it in preference to "Sickle Cell disease". Feedback from Sickle Cell Suffolk also highlighted that many patients and clinicians prefer the term "Sickle Cell Disorder". Terminology varies across organisations and communities, and where possible this profile avoids the term "Sickle Cell disease", recognising these preferences.

Glossary of key terms

Term	Definition
Anaemia	A reduced ability of the blood to carry oxygen, often leading to fatigue and weakness.
Chronic complications	Long-term impacts on health and organs over time.
Haemoglobin	The protein in red blood cells that carries oxygen; abnormal forms lead to Sickle Cell.
Health inequalities	Avoidable, unfair and systematic differences in health between different groups of people.
Red blood cells	Cells that carry oxygen around the body; in Sickle Cell these can become misshapen (sickle shaped) and less effective.
Screening (antenatal and newborn)	Testing during pregnancy and shortly after birth to identify health conditions such as Sickle Cell or carrier status early.
Sickle Cell Disorder/ Sickle Cell Disease (Sickle Cell)	A group of inherited blood disorders where red blood cells are unusually shaped, affecting oxygen delivery and blood flow.
Sickle Cell Trait (SCT)	A genetic condition where a person inherits one Sickle Cell gene and one normal gene. It is not the disorder and typically does not cause significant health problems, although individual experiences may vary.
Vaso-occlusive crisis (pain crisis or Sickle Cell crisis)	Episodes of severe pain caused by sickled cells blocking blood flow in small vessels.

What is Sickle Cell?

Sickle Cell is a serious, lifelong health condition, and is the name for a group of inherited health conditions that affect the red blood cells [2].

People with Sickle Cell produce unusually shaped red blood cells (they look like a sickle or a crescent moon shape). These cells don't live as long as healthy red blood cells (which are round in shape). They can also block the blood vessels causing severe pain and serious health implications.

Normal red blood cells live for about 120 days before they naturally break down, but for Sickle Cells, this is reduced to just 10-20 days. This means that people with Sickle Cell tend to be short of red blood cells and may experience anaemia[3] alongside symptoms such as fatigue and shortness of breath due to insufficient oxygen levels.

Stem cell or bone marrow transplants can potentially cure Sickle Cell, but they are high risk. Other treatments can help manage many of the symptoms[2]. Recent NICE developments indicate a significant shift in the treatment landscape, with the approval of gene editing therapy. More detail is mentioned in the 'NICE guidance' section later in this document.

What causes Sickle Cell?

Sickle cell is genetic and present at birth[4]. It is caused by a gene mutation. The HBB gene provides instructions for making haemoglobin (the molecule in red blood cells responsible for carrying oxygen). An HBB gene mutation leads to the production of abnormal haemoglobin known as haemoglobin S.

Individuals with one normal haemoglobin gene and one haemoglobin S gene have Sickle Cell Trait (SCT) and usually do not exhibit symptoms but can pass the gene to their offspring[5]. When a person inherits two copies of the haemoglobin S gene (one from each parent), or one copy of the haemoglobin S gene and another abnormal haemoglobin variant, they develop Sickle Cell.

Types of Sickle Cell

There are several types of Sickle Cell. The specific type of Sickle Cell a person has depends on the genes they inherited from their parents. Below are the most common types of Sickle Cell[4]:

- **HbSS**: People with HbSS inherit two haemoglobin S genes, one from each parent.
- **HbSC**: People with HbSC inherit a haemoglobin S gene from one parent and a haemoglobin C gene from the other parent.
- **HbS beta thalassaemia:** There are two main forms, HbS beta^0 thalassaemia and HbS beta$^+$ thalassaemia. People with these genotypes inherit a haemoglobin S gene from one parent and a gene for beta thalassaemia from the other parent.

Rarer forms of Sickle Cell include HbSD, HbSE and HbSO.

The genotype describes the form of Sickle Cell a person has inherited, but it does not determine an individual's experience of the condition. The severity and impact of Sickle Cell vary considerably between individuals, even among people with the same genotype.

How is Sickle Cell diagnosed?

A blood test is used to diagnose Sickle Cell. The blood is analysed to see what types of haemoglobin are present in the blood[3].

In England, Scotland and Wales, a national screening programme is in place for Sickle Cell and other haemoglobin disorders. Screening for Sickle Cell disease in pregnancy is offered during pregnancy to check if there's a risk of a child being born with the condition, and all babies are offered screening as part of the newborn blood spot test (heel prick test)[2]:

- **During pregnancy:** Screening for Sickle Cell Disorder is offered during pregnancy in England. In higher-prevalence areas, this involves a blood test to identify carriers; in lower-prevalence areas, a family origin questionnaire is used to determine whether testing is needed, although testing can be requested by anyone. Screening is ideally completed before 10 weeks of pregnancy to allow time for further testing and informed decisions about care and pregnancy[6].
- **Newborn screening:** Newborn screening for Sickle Cell is carried out through the routine blood spot (heel prick) test. It helps identify babies with the condition or carrier status, including those not detected through antenatal screening. If results suggest Sickle Cell, a follow-up blood test is done to confirm the diagnosis [6].
- **Carriers:** A blood test can be done at any time to find out if an individual carries Sickle Cell Trait. If someone with SCT becomes pregnant with a partner who has Sickle Cell or SCT, there is a risk the baby could inherit Sickle Cell or SCT.

Who is most affected and why?

The condition is more common among people with ancestry from regions where malaria has historically been endemic, including sub-Saharan Africa. It is also seen in populations originating from the Middle East, parts of India, the eastern Mediterranean and other parts of Europe[1], and Central and South America.

This distribution reflects a well-established protective effect of the Sickle Cell Trait against malaria, which has led to higher prevalence of the gene in these populations. As a result of migration and increasingly diverse populations, Sickle Cell is now a global health issue and an important consideration for health services across England.

In the UK, around 8% of Black individuals are estimated to carry the Sickle Cell Trait. Prevalence is also increasing in people with mixed ethnic backgrounds, reflecting changing population patterns. Recent data from the Sickle Cell Society highlights[7]:

- Approximately 1 in 79 babies born in the UK carry Sickle Cell Trait.
- 250 babies are born each year with Sickle Cell.
- Approximately 19,000 people in the UK have Sickle Cell Disorder.
- Sickle cell trait is found in 1 in 4 West Africans and 1 in 10 African-Caribbeans, and is also found in people who originate from the Mediterranean, Asia and the Middle East. It is less common in White Europeans (although there are parts of Europe where Sickle Cell is present), and with the ever-growing diversity of the population this will change.

What are the symptoms of Sickle Cell?

Many individuals with Sickle Cell experience symptoms from early childhood, but it is possible that some children have few symptoms and may lead 'normal' lives most of the time.
Some symptoms include [2,3,5]:

- **Vaso-occlusive crisis (Sickle Cell crisis).** This is when the sickled cells clump together or stick to the side of blood vessels. This can block the blood vessels and cause severe pain and sudden onset of various symptoms
- **Anaemia** that can cause tiredness / exhaustion and shortness of breath, as the sickled blood cells cannot carry enough oxygen around the body
- **Swelling**: particularly in the hands and feet. This is known as dactylitis and is often the first symptom in babies
- **Spleen damage** which makes patients more susceptible to infections such as pneumonia
- **Delayed growth / puberty** in children and young people due to chronic anaemia and other complications
- **Vision problems** due to blocked blood vessels in the eyes, which can lead to damage to the retina

Babies with Sickle Cell typically show no symptoms until around 3–6 months of age, when foetal haemoglobin declines and is replaced by haemoglobin that can sickle.

Symptoms vary in frequency and severity. Some people have few or mild symptoms, while others experience severe complications, chronic and acute pain requiring hospital care.

The National Institute for Health and Care Excellence (NICE), highlights the following in terms of prognosis[8]:

- Childhood mortality for those with Sickle Cell in the UK is relatively rare, with 99% of children surviving to adulthood. However, in Africa 50–90% of children with Sickle Cell die before the age of 5 years.
- People with frequent pain episodes or other comorbidities are more likely to die early.
- Evidence indicates that Sickle Cell can reduce life expectancy, although outcomes vary considerably between individuals and estimates differ by study, genotype, treatment and health system.

How is Sickle Cell treated?

The NHS[2] notes that Sickle Cell usually requires lifelong management, typically coordinated through specialist multidisciplinary teams and supported by individual care plans. Treatment focuses on preventing complications, managing symptoms, and responding to acute episodes.

Preventative approaches include avoiding known triggers (such as dehydration, cold exposure, and sudden temperature changes), routine vaccinations (especially for children), and long-term antibiotics to reduce the risk of serious infections. Folic acid is also used to replace depleted folate stores and reduce symptoms of anaemia.

Medications such as hydroxycarbamide may be used to reduce the frequency and severity of pain episodes, with regular monitoring required. Hydroxycarbamide reduces sickling, inflammation, and blood vessel blockage, helping improve blood flow and prevent painful episodes[9]. Regular monitoring

is needed because Hydroxycarbamide can also lower the amount of other blood cells, such as white blood cells (that fight and help to prevent infection) and platelets (clotting cells).

Pain management is a central aspect of care. Many people manage milder pain episodes at home through medication, hydration, warmth, and rest, while more severe crises may require hospital treatment, including strong pain relief and supportive care. Blood transfusions are used in some individuals to manage severe anaemia or complications such as stroke risk.

Sickle cell can lead to a range of acute and long-term complications, requiring targeted treatment (for example, acute chest syndrome, stroke prevention, or chronic organ damage).

Complications of Sickle Cell
Sickle cell can lead to a range of additional complications across the life course, many of which require targeted treatment or specialist management.

Examples include:

- **Delayed puberty**, which may be treated with short courses of hormonal therapy
- **Gallstones**, sometimes requiring surgical removal of the gallbladder
- **Bone and joint complications /Avascular Necrosis** (death of bone tissue due to loss of blood supply) ranging from chronic pain and mobility issues, sometimes requiring surgical intervention
- **Priapism** (persistent, painful erections), which may need urgent medical treatment
- **Leg ulcers**, managed through wound care and dressings
- **Increased risk of stroke**, which may be managed through regular blood transfusions or medication such as hydroxycarbamide
- **Acute chest syndrome**, a serious lung complication requiring urgent treatment with antibiotics, oxygen, fluids, and sometimes blood transfusions

Regular blood transfusions every 4 to 6 weeks are one of the ways to prevent or help the symptoms of Sickle Cell. In recent years NHS Blood and Transplant note that more and more people with Sickle Cell have started having red cell exchange transfusions[10]. People receiving frequent blood transfusions may also require chelation therapy - this reduces the amount of iron in their blood to safe levels.

Stem cell or bone marrow transplantation can potentially cure Sickle Cell but carries significant risks and is suitable only for selected patients. Recently approved gene-editing therapy represents a further potentially curative option for a limited group of eligible patients.

Stem cells are special cells produced by bone marrow which turn into different types of blood cells. Stem cells from a healthy donor are given through a drip into a vein, and these cells then start to produce healthy red blood cells to replace the sickled cells. Stem cell transplants are generally only considered in children with Sickle Cell who have severe symptoms that have not responded to other treatments, when the long-term benefits of a transplant are thought to outweigh the possible risks.

Overall, effective management of Sickle Cell relies on a combination of preventative care, responsive treatment, and access to specialist services, alongside support for people to manage their condition in everyday life.

NICE guidance

The main NICE clinical guideline for Sickle Cell (CG143) was published in 2012 and has not been comprehensively updated, although newer evidence has been incorporated into NICE Clinical Knowledge Summaries (CKS). This gap may contribute to variation in care and reflects wider challenges in the pace of investment and development of guidance for Sickle Cell.

The goals of the CKS summary were to support primary healthcare professionals to:

- Identify people with Sickle Cell and Sickle Cell Trait.
- Identify a Sickle Cell crisis and ensure appropriate treatment is given, including admission (if appropriate).
- Advise on measures to prevent (or reduce the risk of) complications of Sickle Cell.
- Provide support to people with chronic complications of Sickle Cell in primary care.
- Help people with Sickle Cell understand how to manage their illness and when to seek urgent medical advice.

However, no outcome measures were noted in the CKS.

Recent NICE developments indicate a significant shift in the treatment landscape, with the approval of gene editing therapy (exagamglogene autotemcel, or exa-cel/Casgevy) for some people with severe Sickle Cell. This therapy offers the potential for a cure by enabling the body to produce healthier red blood cells, and is being introduced in England through a managed access scheme while further evidence is collected. While this represents an important step forward, access is currently limited to a small number of patients with severe Sickle Cell Disorder, and wider population-level impact will take time to understand.

Importantly, NICE's decision-making has explicitly considered the impact of Sickle Cell on health inequalities, recognising that the condition disproportionately affects people from African, Caribbean, Middle Eastern or South Asian family backgrounds. The approval of exa-cel reflects a broader attempt to address longstanding inequities in treatment options and investment. However, the limited eligibility, complexity of delivery, and ongoing uncertainty in the evidence base mean that this innovation alone is unlikely to address the wider inequalities described in this profile, particularly those related to access, experience of care, and variation in services.

A more detailed 2026 NICE article on the impact of gene therapy for Sickle Cell can be found via this link.

West Midlands Sickle Cell and Thalassaemia Network (WMSTN) have developed a range of information leaflets that are helpful to both patients and professionals.

A 2026 NHS England blog highlighted the Sickle Cell Disease Clinical Pathway Initiative (CPI) - A framework that sets out the knowledge and skills healthcare professionals need to support people with Sickle Cell at key points in their lives.

Key health inequalities

Despite being a serious long-term condition, people living with Sickle Cell often experience inequalities in how and when they receive care, as well as in their overall health outcomes. These differences are shaped by variation in services, gaps in awareness and wider structural inequalities, including those related to ethnicity.

What are health inequalities?

Avoidable, unfair and systematic differences in health between different groups of people.

Source: The Kings Fund (2025)

Examples of health inequalities faced[11–13]:

1. Inequitable access to high-quality care

- People with Sickle Cell often experience variation in care depending on where they live, reflecting differences in local expertise, service configuration and access to specialist services. Areas with higher prevalence may have more established services and greater clinical familiarity; however, higher prevalence alone does not guarantee good care. Reports[14] have highlighted poor patient experiences, delays in treatment and avoidable deaths even in areas with relatively large Sickle Cell populations
- Access to specialist teams and clinicians is more limited compared with other long-term conditions

2. Poorer experiences within healthcare

- Many patients report negative hospital experiences, including delays in treatment, inconsistent care and a lack of empathy
- Reports highlight substandard care and gaps in staff knowledge about the condition - especially GPs in relation to pain management, but also in A&E
- Some individuals experience stigma or discrimination, including assumptions about pain or drug-seeking behaviour

3. Racial and structural inequalities

- Sickle cell predominantly affects people of Black African and Caribbean heritage, and inequalities are linked to structural racism and bias within healthcare systems
- This contributes to a breakdown in trust and avoidance of services among some patients

4. Underinvestment in services and research

- Compared with other conditions such as cystic fibrosis[1], Sickle Cell receives less research funding, fewer treatment options, and fewer specialist staff
- Long-standing under-resourcing and lower prioritisation have been identified as systemic issues

5. Barriers to timely and appropriate treatment

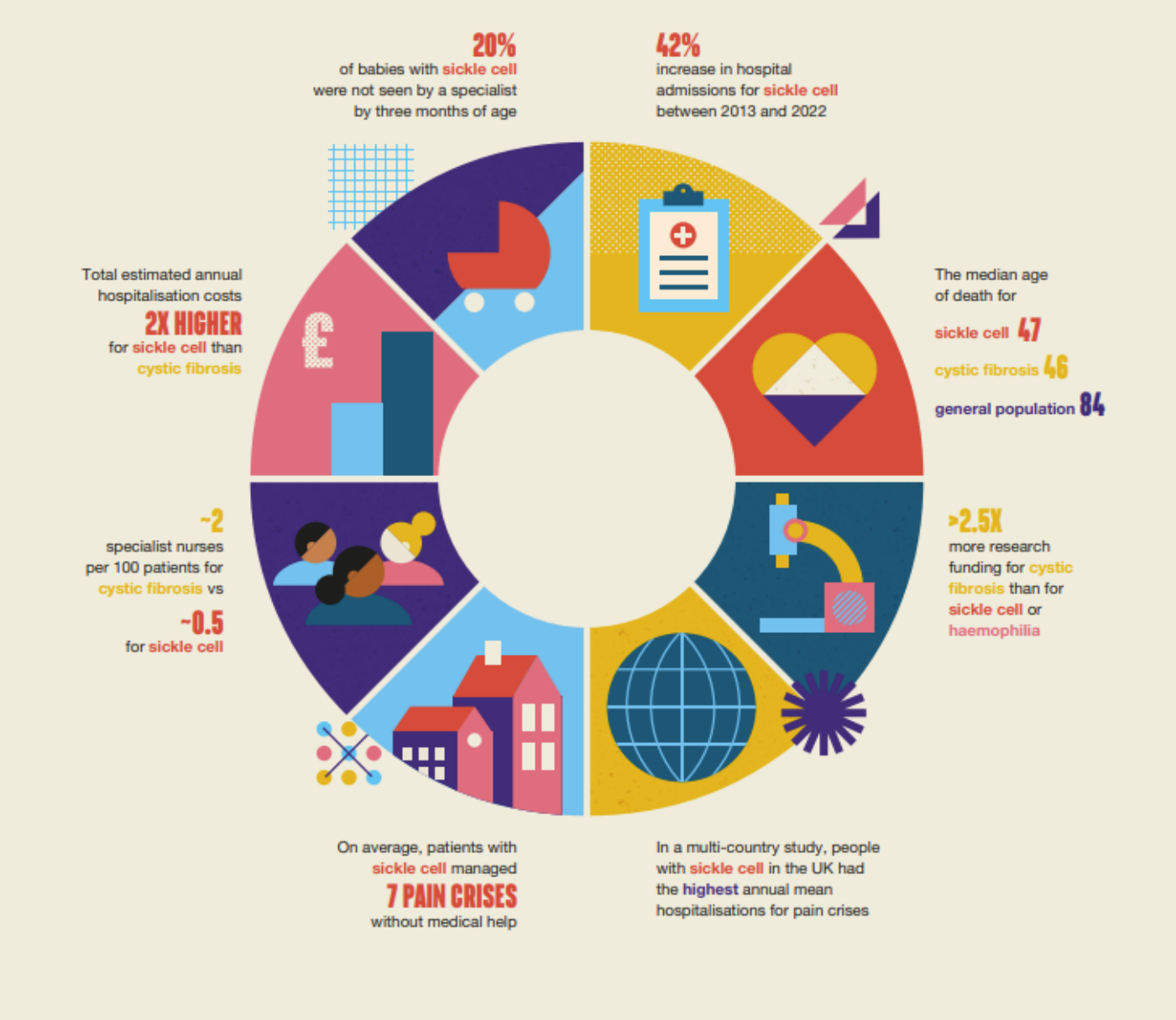
- Patients may experience delays in pain relief during acute crises, despite clear clinical guidelines (2012 NICE guidelines indicating that pain relief should be offered within 30 minutes of presentation with an acute painful Sickle Cell episode in hospital)
- Previous negative experiences can lead people to avoid seeking care, worsening outcomes

6. Poorer outcomes

- Sickle cell is associated with higher hospital use and ongoing complications, reflecting potentially both unmet need and poorer clinical condition management
- Evidence suggests substantial impacts on quality of life and life expectancy, although outcomes vary

[1] Chosen by researchers as a comparator due to similar population sizes, and because both conditions are also included in the universal newborn screening programme in place in the UK.

Figure 1: Summary of key data related to Sickle Cell health inequalities



Source: Imperial, Sickle Cell Society, NHS Race &Health Observatory (2025)

What the local data tells us

Publicly available data on Sickle Cell is limited. As an example, NHS England produces the Sickle Cell and Thalassaemia Screening (SCT) annual standards data table, with the latest data being from 2024/25. This is broken down to trust level, but as can be seen in the data below, much of the local trust data is suppressed due to low numbers (designated by a [u] in the table). Additionally, whilst this is a component of understanding Sickle Cell locally, this data is related to performance and timeliness of screening, rather than understanding the wider population health impacts.

Table 1: Summary indicators of the antenatal screening standards: data report 2024 to 2025, England and main providers serving Suffolk populations.

	SCT-S01 - Antenatal Sickle Cell and thalassaemia screening - coverage			SCT-S06 - Antenatal Sickle Cell and thalassaemia screening - timeliness of prenatal diagnosis (PND)			SCT-S07 - Antenatal Sickle Cell and thalassaemia screening - timely reporting of prenatal diagnosis (PND) results to parents		
Provider Name	**Tested women**	**Eligible women**	**Performance**	**Women who have PND in time**	**Women who have PND**	**Performance**	**Women who receive PND result in time**	**Women who have PND**	**Performance**
England	618,573	619,890	99.8%	250	705	35.5%	420	640	65.6%
East Suffolk and North Essex NHS Foundation Trust	7,277	7,292	99.8%				5	10	[u]
James Paget University Hospitals NHS Foundation Trust	1,840	1,842	99.9%				5	5	[u]
West Suffolk NHS Foundation Trust	2,442	2,443	100.0%				0	0	

Note: [u] denotes data not available due to low reliability, where the rounded denominator is 20 or less, the performance has not been calculated. Blanks- no data.
Source: NHS England via GOV.UK

Limited information on Personal Independence Payments (PIP) for Sickle Cell is available via Stat Xplore. Numbers of PIP cases with entitlement where Sickle Cell as the listed disability in Suffolk were <10 across multiple years (see table 2 below). Many of the cells are blank indicating either no data or suppression due to small numbers. Ipswich is the only Lower Tier Local Authority (LTLAs) where data can be published, and even then, numbers are small (last publishable data 5 claimants in April 2025). Although conclusions are limited by very small numbers and data suppression, the low recorded caseload may not capture the full level of need. There is a possibility of under-claiming, which would be consistent with broader inequalities in income, awareness, and access to support among people living with long-term conditions.

Table 2: Personal Independence Payments (PIP) with entitlement for Sickle Cell, by Suffolk LTLA, 2019-2026.

	Month and Year							
	Apr-19	**Apr-20**	**Apr-21**	**Apr-22**	**Apr-23**	**Apr-24**	**Apr-25**	**Apr-26**
Babergh								
Ipswich			5	5	6	6	5	
Mid Suffolk								
East Suffolk								
West Suffolk								
Total	**6**	**5**	**9**	**6**	**9**	**8**	**9**	**5**

Source: Stat Xplore (2026)

Population Health Management (PHM) data

PHM data is a linked, person-level dataset that brings together de-identified information from multiple health and care services (e.g. GP, hospital, mental health, community and adult social care), enabling analysis of health needs, risk factors, service use and inequalities across the population.

This data has been explored in relation to Sickle Cell. Detailed PHM data is available for Suffolk residents (excluding Waveney) (from here on in called the SeW (Suffolk excluding Waveney) PHM data). An information request was also submitted to Norfolk colleagues to gather data on the number of residents in the Waveney area with Sickle Cell, as although Waveney is in Suffolk, PHM data relating to that population was previously held within Norfolk systems under the Norfolk & Waveney ICB.

- As of February 2026, 11 people were recorded as having Sickle Cell in the Waveney area. However, detailed demographic data was not available at the time of the request, and ethnicity data was not captured for 64% of this cohort – representing an area for improvement.
- For SeW, data captured between January and December 2025 identified 78 people with a Sickle Cell diagnosis. Further demographic breakdowns are provided on the following pages.

This suggests a minimum identified population of around 89 people with Sickle Cell across Suffolk. However, a more recent PHM extract (June 2026) which includes Waveney (but uses a different reporting system) indicates a higher estimate of approximately 119 people. This figure is subject to ongoing data quality checks.

This suggests the true number of people living with Sickle Cell in Suffolk is likely to fall within a range of approximately 90 to 120 individuals, though this should be interpreted with caution due to known data limitations. For the purposes of this profile, the more consistent and detailed SeW PHM dataset has been used for detailed analysis (n=78).

Demographic overview

The number of people identified with diagnosed Sickle Cell in the SeW PHM dataset is small (n=78), which limits the level of detail that can be reported and interpreted robustly. Small cohort sizes may result in considerable variation and may also create a risk of inadvertent disclosure. For that reason, some detailed breakdowns have not been presented. The analysis below is therefore best understood as a high-level exploration of key themes within the data.

Table 3 below provides more detail on differences between those with a Sickle Cell diagnosis and the SeW cohort as a whole. **Differences highlighted here are indicative and based on small numbers; where shading is shown, this reflects notable variation between groups rather than statistically tested differences.**

Findings include:

Younger cohort, with higher deprivation and a different ethnic profile

- People with a Sickle Cell diagnosis are notably younger on average than the Suffolk population as a whole (27 vs 43 years).
- In the PHM dataset, 97% of the Sickle Cell cohort are recorded within the dataset's "Minority Ethnic" category, compared with 11% of the wider population. "Minority Ethnic" is the categorisation used within the source PHM dashboard and refers to ethnic groups other than White British, White Irish and White Other.
- This is consistent with the known demographic profile of the condition. More detailed ethnicity data (not tabled) indicate that over half of the cohort (56.4%) identified as Black African, with smaller proportions identifying as Black Caribbean or Black Other ethnic groups.
- Deprivation is typically higher in the Sickle Cell population compared to SeW as a whole – with an average deprivation score of 4.8 for people with a Sickle Cell diagnosis, compared to 6.0 for SeW (on a scale where 1 is the highest level of deprivation, 10 the lowest).

Substantially higher healthcare use and cost

- Despite a younger age profile, healthcare costs are substantially higher, likely reflecting condition-specific care needs.
- Healthcare spend is markedly higher across all categories for those with Sickle Cell, with total annual costs around five times higher than the wider population. This is driven by both urgent and emergency care and planned acute activity, indicating high clinical need and ongoing management requirements.

Different pattern of long-term conditions

The diagnosed Sickle Cell cohort shows:

- Higher prevalence of conditions linked to Sickle Cell complications, including cardiovascular disease, kidney disease, stroke and transient ischaemic attack
- Lower recorded prevalence of some common long-term conditions (e.g. asthma, diabetes, hypertension, obesity), likely reflecting the younger age profile rather than lower underlying risk
- Lower recorded prevalence of chronic pain than in the wider population, despite pain being a major feature of Sickle Cell. This may indicate differences in coding or recording and should not be interpreted as evidence of lower pain-related need.

Neurological and vascular complications stand out

The percentage of stroke (5.1% vs 1.4%), Transient Ischaemic Attacks (TIA), and related conditions are notably higher in the population with Sickle Cell compared with the general population, aligning with known risks such as cerebrovascular complications.

Mental health recording appears lower

Recorded prevalence of anxiety and depression is substantially lower than the wider population. This may reflect under-identification, under-recording, or differences in help-seeking, rather than true lower need[15,16].

Higher prevalence of some infectious and rarer conditions

- Tuberculosis and recent Covid recording are higher in the Sickle Cell cohort
- Some rare conditions (e.g. Raynaud's, Parkinson's) appear to be higher in the Sickle Cell cohort, though interpretation is limited by very small numbers

Mixed picture on risk factors and behaviours

- Alcohol and substance misuse and high cholesterol are lower in the Sickle Cell cohort, again likely influenced by age and recording patterns
- Opioid prescribing is higher in the Sickle Cell cohort, consistent with pain management needs

The overall pattern suggests that people with Sickle Cell in Suffolk (excluding Waveney) experience high levels of clinical complexity and healthcare utilisation, with a distinct profile driven by disorder-specific complications, younger age, and potential gaps in recording, diagnosis and treatment for some conditions such as mental health.

Other characteristics noted from the data but not included in the table below:

- Only 20.5% of those with Sickle Cell were in the 'low' deprivation cohort, with the remaining 79.5% living in areas of either medium or high deprivation
- Over 90% of the cohort lived in non-coastal areas (more precise percentage redacted due to potential disclosure)
- When looking at which Integrated Neighbourhood Team (INT) areas had the highest registered cohort population, Ipswich East and Ipswich West INTs had the highest numbers (combined value of 48 registered patients – 61.5% of the total cohort).

Note: Percentages should be interpreted cautiously due to small cohort size. Not tested for statistical significance. Purple shading reflects notable variation between groups rather than statistically tested differences.

Table 3: Key indicators for Sickle Cell cohort compared to the wider SeW population, January-December 2025

Age Band (Life Stage)	Cohort Population (those with a Sickle Cell diagnosis)	Whole Suffolk exc. Waveney (SeW) Population
Overall Population Measure		
Average Age	27.2	43.6
Male[2] Percentage	42.3	50.0
Deprivation (lower = more deprived)	4.8	6.0
Minority Ethnic[3]	97.4	11.1
Avg. Multimorbidities	0.5	0.9
Outcomes - Overview		
Finance Per person per year - Total	£ 9,816.89	£ 1,986.07
Urgent & Emergency	£ 2,802.38	£ 313.27
Acute Planned	£ 5,133.73	£ 388.35
Physical Health		
Asthma	3.9%	10.9%
Cardiovascular Diseases	10.3%	8.1%
Chronic Kidney Disease	7.7%	5.2%
Chronic Pain	6.4%	10.2%
COPD	0.0%	2.6%
Diabetes	3.9%	6.9%
Hypertension	15.4%	18.9%
Migraine (In Year)	2.6%	0.9%
Obesity	12.8%	16.5%
Parkinson's Disease	1.3%	0.3%
Raynaud's Phenomenon	1.3%	0.9%
Stroke	5.1%	1.4%
Transient Ischaemic Attack	1.3%	0.9%
Tuberculosis	1.3%	0.0%
Mental Health & Learning Disability		
Anxiety	2.6%	17.0%
Depression	2.6%	13.2%
Other Characteristics		
Alcohol & Substance Misuse	2.6%	6.8%
Had Covid	10.3%	3.4%
High Cholesterol	5.1%	19.1%
Opioid Prescription	9.0%	6.4%
Palliative Care	1.3%	0.6%

Source: Optum Pathfinder Dashboard (June 2026)

[2] The source PHM dashboard presents sex as a binary variable and reports only the percentage of the cohort recorded as male. The percentage recorded as female can therefore be inferred as the remainder to 100%. Due to the small cohort size, sex differences should be interpreted with caution and viewed as descriptive rather than definitive.

[3] "Minority Ethnic" is the categorisation used within the source PHM dashboard and refers to ethnic groups other than White British, White Irish and White Other.

Lived experience and voice

Watch this short video from the NHS about Sickle Cell Disease, and its impact:

Source: NHS (2026)

Junior:
"Your legs hurt, your arms hurt, you can't walk or do anything...

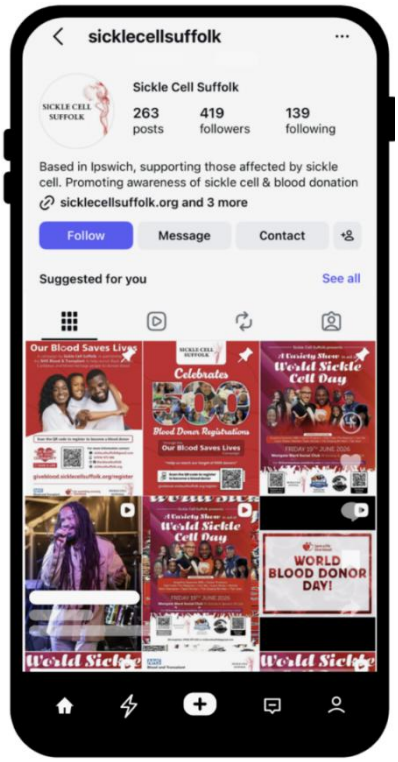
...So you have a lot of time off school and because it affects a minority, mainly Afro-Caribbeans, a lot of the schools don't research it, they don't know about it.... It affects your career, it affects your ambition, it affects your money, it affects your wallet. It affects everything, basically...

It is a challenge to actually live with the condition but it's a challenge that all of us really relish and it doesn't stop you from enjoying your life"

Sickle Cell Suffolk

Sickle Cell Suffolk is a community-led group based in Ipswich, supporting people affected by Sickle Cell across Suffolk. Established in 2014 by individuals with lived experience of the condition, the group aims to raise awareness, share insight with local services, and improve care. They work to amplify the voices of people living with Sickle Cell, alongside promoting understanding of Sickle Cell Trait within the community.

Sickle Cell Suffolk also collaborates with organisations including NHS Blood and Transplant to encourage blood donation among Black African, Caribbean and Mixed Heritage communities, where matched donors are most needed. Their development has been supported locally by partners, and they continue to play an important role in highlighting lived experience and shaping local awareness and support.



In 2026, Elaine Tappin, Sickle Cell Suffolk's lead Co-ordinator, shared some of her lived experience as part of the creation of this JSNA profile:

"Living with sickle cell is difficult to explain to someone who has never experienced it.

I live with the uncertainty and anxiety of not knowing when a sickle cell crisis may occur, how severe it will be, how long it will last and the effects. I can appear well on the outside while experiencing significant pain, exhaustion and other effects of the condition. Its impact on my life is very real.

Sickle Cell affects my energy, sleep, mobility, independence and ability to make plans. I may have to cancel commitments or change plans because my body simply will not allow me to do what I had intended.

The pain of a crisis can be indescribable. For me, it can feel as though someone is constantly pounding my joints with a hammer while simultaneously driving a tool into the exact areas being hit. The pain can be variable and last for hours, days and sometimes even weeks.

One of the hardest aspects is the lack of knowledge by health professionals, the lack of care, help, empathy and not being believed.

My experiences and that of others, has made me passionate about raising awareness and advocating for people living with sickle cell. Through Sickle Cell Suffolk, I want others to know they are not alone, and to help the national agenda to create greater awareness and that people with sickle cell are listened to, believed, understood, treated with compassion, empathy, care and dignity".

Lead Coordinator - Sickle Cell Suffolk
Sickle Cell Patient, Expert Patient, Advocate & Speaker
Member of the Red Cell Network Patient Public Voice Group
Member of the All Party Parliamentary Group on Sickle Cell and Thalassemia
Member of the European Sickle Cell Federation

Source: Elaine Tappin 2026

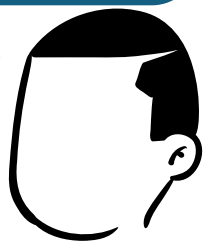
In 2021, the All-Party Parliamentary Group on Sickle Cell and Thalassaemia (SCTAPPG) published the inquiry report 'No One's Listening'[17]. The report examined the level of care Sickle Cell patients receive when accessing secondary care and aimed to determine the action required to improve care for Sickle Cell patients. Key findings highlighted:

- Sickle cell patients too often receive sub-standard care, with significant variations in care depending on which staff happen to be on duty or which area of the country a patient was in
- Care failings have led to patient deaths over decades and 'near misses' were not uncommon
- A significant factor in the sub-standard care Sickle Cell patients often receive is a lack of effective joined up care.
- Community care for Sickle Cell patients was generally inadequate or non-existent and led to unnecessary admissions to hospitals.
- Wider system issues—including racism, stigma, inadequate community provision, and long-term underinvestment—contribute to poorer experiences and outcomes

Sickle Cell Suffolk contributed to this report – comments provided by Sickle Cell Suffolk are included below:

"Once we are admitted to a ward we have to ask the ward [whether they] have advised the haematology department we have been admitted. The response is always 'not yet'. It is our experience that the haematologist visits the patient on day three. This is not adequate [and] is purely because they have not been made aware."

"Better communication is needed between staff. You communicate with one staff member and they do not tell others or write it down, therefore we are always explaining things to different staff"



Sickle Cell Suffolk told us [the inquiry] that in their experience of a local hospital, "the haematology staff do not have enough knowledge on Sickle Cell and are not able to advise the medical staff adequately", citing an incident where one of their members was on a general ward and "the haematologist asked the nursing staff why she was on a fluid drip … Given this is a basic need for a Sickle Cell patient, it did not fill the patient with confidence about her care."

Recommendations from the inquiry included ensuring compliance with NICE guidance around pain relief, the development of guidance for A&E staff that prioritises Sickle Cell patients (due to the risk of rapid deterioration in this cohort), and the development of e-learning about the standards of care. Another recommendation specifically recommended that haematology teams are routinely alerted to Sickle Cell admissions so expert input informs care and is monitored through national quality systems.

Case studies from other sources

Case study: living with Sickle Cell in Suffolk (adapted from BBC News article)

Vivica, a teenager from Ipswich who attended Chantry Academy, lived with Sickle Cell and experienced severe pain episodes and frequent contact with specialist services across multiple hospitals, including Ipswich, Cambridge and London. Her condition required ongoing management and had a significant impact on both her day-to-day life and her family.

Following a bone marrow transplant from her sister, there was hope that her health would improve. However, her condition deteriorated unexpectedly and she died shortly afterwards, which her family described as a profound shock after years of managing the condition.

Her family have spoken about the physical and emotional toll of Sickle Cell, as well as occasions where understanding of the condition varied across services. In Vivica's memory, they are now working to raise awareness of Sickle Cell and support other children and families affected.

Why this case study is important:

- Awareness and understanding of Sickle Cell can vary across services, highlighting a need for consistent knowledge and training
- Individuals may require care across multiple specialist centres, emphasising the importance of coordinated pathways
- The impact extends beyond the individual, with significant emotional and practical effects on families
- Conditions affecting smaller populations can be overlooked, reinforcing the need to actively include lived experience in local insight and planning

Source: BBC News (2025)

Case study: living with Sickle Cell in Suffolk (adapted from the Ipswich Star)

Nadine dos Santos, a 30-year-old woman living in Ipswich, was diagnosed with Sickle Cell when she was six months old. She experienced severe and ongoing pain, which she managed day-to-day with medication.

The day before her death, she attended hospital during a Sickle Cell crisis and later returned home. The following day, after contacting her family in distress due to pain, she was found unresponsive at home and died later that evening.

A postmortem found that she had experienced a pulmonary embolism. People with Sickle Cell can be at increased risk of complications of this kind.

Her experience highlights the unpredictable nature of Sickle Cell, the severity of pain associated with crises, and the ongoing risks faced even by adults who have lived with the condition for many years. It also illustrates the importance of timely support during acute episodes and the potential for rapid deterioration.

Why this case study is important:

- Sickle cell crises can involve severe pain and rapid deterioration, highlighting the importance of timely assessment, escalation and support during acute episodes
- Individuals may access urgent care but still experience ongoing risk, emphasising the need for continuity of care and clear safety-netting
- There is an increased risk of serious complications (e.g. blood clots), reinforcing the importance of clinical awareness and proactive management
- The lived experience of adults with long-term conditions can remain largely unseen, underlining the need to include their perspectives in local insight and service planning

Source: Ipswich Star (2023)

How can this lived experience inform commissioning?

Services should:

- Ensure clear, consistent urgent care pathways for Sickle Cell crises, including effective pain management and escalation protocols across settings
- Strengthen continuity of care between acute, specialist and community services, with clear safety-netting following discharge
- Invest in workforce training to improve recognition of complications (e.g. thrombotic risk) and reduce variation in clinical understanding
- Promote compassionate, person-centred care: Support healthcare professionals to recognise the impact of Sickle Cell on daily life and ensure people presenting with pain or other symptoms are listened to, believed and treated with empathy and respect.
- Prioritise proactive engagement with people living with Sickle Cell to inform service design, particularly for adults managing long-term risk

ACT NOW: improving the response to Sickle Cell crisis

The NHS has introduced the **ACT NOW** approach to support a rapid and effective response when people with Sickle Cell present to hospital in crisis[18]. The initiative was co-developed with clinicians, people living with Sickle Cell, families and other experts in response to concerns highlighted in the *No One's Listening* report, which identified avoidable deaths and failures in care.

ACT NOW provides a simple framework to help emergency departments, ambulance services, acute wards and bypass units recognise and respond quickly to Sickle Cell crises. The aim is to improve both patient experience and clinical outcomes by promoting timely assessment, effective pain management, escalation when required, and greater awareness among healthcare professionals.

The approach is supported by NHS England, is included within The Royal College of Emergency Medicine best practice guidance, and is accompanied by education and training resources designed to improve staff confidence and knowledge in caring for people with Sickle Cell.

Why ACT NOW matters

The initiative directly addresses several of the challenges identified throughout this profile, including:

- Delays in pain relief and treatment during Sickle Cell crises
- Variation in staff knowledge and confidence
- Poor patient experiences and reports of not feeling listened to or believed
- The need for consistent, high-quality care regardless of where a person presents for treatment.
- Wider health inequalities experienced by people living with Sickle Cell

Conclusion

Although the number of people living with Sickle Cell in Suffolk is relatively small, the evidence shows a population with complex, lifelong health needs and significantly higher use of healthcare services. For individuals and families, this translates into ongoing management of pain, risk of serious complications, and the need to navigate multiple services over time. Lived experience highlights that this journey is not always consistent, with variation in care, awareness and support shaping both outcomes and trust in the system.

Compared to the Suffolk population overall, the data reflects a younger population, with a much higher proportion of people from Black African, Black Caribbean and other non-White British ethnic backgrounds, alongside higher levels of deprivation. This reinforces the importance of understanding Sickle Cell within the context of health inequalities. Patterns such as higher prevalence of vascular complications, increased healthcare costs, and potential under-recognition of mental health needs suggest a distinct and sometimes hidden burden that may not be fully captured through routine data alone.

For professionals and services, the findings point to challenges in coordination, knowledge, empathy and continuity of care. Variation in awareness, particularly outside specialist settings, alongside gaps between acute, community and primary care, can result in fragmented pathways. Lived experience evidence highlights that some people with Sickle Cell do not always feel listened to or believed when presenting with pain or other symptoms. Wider barriers such as stigma, inconsistent follow-up, and limited visibility of the condition further contribute to variability in experience and outcomes.

From a public health and commissioning perspective, this profile highlights that small numbers do not equate to low need. Instead, it points to a group where inequalities are shaped by a combination of clinical complexity, structural factors, and historical underinvestment. The key "so what" is the need to ensure that people with Sickle Cell are visible within local planning, with services that are connected, informed by lived experience, and able to respond consistently across the life course.

What needs to happen next?

Based on the evidence presented in this profile, priorities for action include:

- **Small population, high need:** Ensure people with Sickle Cell are explicitly considered in commissioning and planning despite low numbers.
- **Improve care consistency:** Strengthen urgent care pathways and adherence to NICE guidance, including promoting awareness and implementation of the ACT NOW approach to support rapid assessment and treatment during Sickle Cell crises.
- **Build workforce knowledge:** Ensure awareness of Sickle Cell for primary care, A&E and general wards to reduce variation in understanding and treatment.
- **Strengthen coordination of care:** Improve links between specialist, acute and community services, including clearer handovers and follow-up.
- **Promote compassionate, person-centred care:** Ensure people presenting with Sickle Cell symptoms or pain crises are listened to, treated with empathy and respect, and receive timely, evidence-based care.
- **Use lived experience to shape services:** Continue working with groups such as Sickle Cell Suffolk to inform service design and improvement.
- **Address inequalities and trust:** Recognise the impact of structural inequalities and stigma and prioritise culturally competent care and engagement.
- **Improve data quality and visibility**: Strengthen coding, ethnicity recording and local data completeness to better understand need and outcomes.
- **Consider mental health alongside physical health**: Improve identification and support for mental health needs, recognising likely under-recording and potential under-diagnosis.
- **Promote awareness of Sickle Cell Trait and existing services:** Improve understanding of inheritance, screening and support pathways among communities and professionals.

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