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SICKLE CELL PATIENTS' EXPERIENCES OF THE LONDON AMBULANCE SERVICE

Findings of a research project - commissioned by London Ambulance Service NHS Trust and carried out by the Sickle Cell Society - into sickle cell patients' experiences of ambulance care and 999 & 111 calls in London

SICKLE CELL SOCIETY

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BACKGROUND

In January 2024, London Ambulance Service commissioned the Sickle Cell Society to undertake a research project to find out more about sickle cell patients' experiences of using its services, including ambulance care and 999 and 111 calls.

The project followed recent research into the standard of care sickle cell patients receive, including the Sickle Cell Society and All-Party Parliamentary Group on Sickle Cell and Thalassaemia's No One's Listening report and the NHS Race and Health Observatory's Designing Better Acute Painful Sickle Cell Care report.

Following on from these examinations of sickle cell care, London Ambulance Service commissioned this research project to shed light on pre-hospital care and to support its efforts to ensure it is delivering high-quality care to sickle cell patients using its services.

London Ambulance Service attends approximately 5,700 callouts per year from sickle cell patients in London, which is the most high prevalence area for the condition in the UK. As a service which is often the first point of contact for sickle cell patients in crisis, improvements to the service are likely to play a significant role in improving outcomes for people living with sickle cell and as part of wider efforts to tackle health inequalities.

METHODOLOGY

A total of 53 individuals provided contributions that informed this report, which were obtained through a number of different engagement approaches.

The Sickle Cell Society would like to thank all those who took the time to share their experiences, perspectives and recommendations for this project.

Three focus groups took place, facilitated by the Sickle Cell Society's project coordinator, Aidan Rylatt:

- Focus group with the Solace Support Group at Homerton Hospital in Hackney on Tuesday 16th April 2024, featuring nine participants (four in-person and five joining via online video-link).
- Online focus group (via Zoom) on Thursday 16th May 2024, featuring 12 participants (ten of whom were sickle cell patients, two with a professional interest in sickle cell), recruited via promotion through Sickle Cell Society (and partners') communication channels.
- Focus group with the West London Haemoglobinopathy Coordinating Centre Patient and Public Voice Group (conducted via Microsoft Teams) on Thursday 30th May 2024, attended by a total of 16 people, including nine sickle cell patients/carers/relatives and seven people with a professional interest in sickle cell.

Each focus group began with an introduction to the project. Participants were then asked questions regarding their perceptions of and experiences with London Ambulance Service, as well as their recommendations for how LAS can best support sickle cell patients. Representatives from LAS attended for part of each focus group to provide an overview of why the project had been commissioned and its plans to act on the findings. To ensure it was a patient-led process and that participants had space to openly share their experiences, it was agreed between the Sickle Cell Society and LAS that each focus group also featured time for discussion without an LAS representative present.

In addition to the focus groups, two one-to-ones interviews were held – one with an individual involved with the London Ambulance Service Patients' Forum and past LAS sickle cell consultations; one with a sickle cell patient (and patient advocate) – and one group interview with three specialist sickle cell nurses.

A 'call for written submissions' was published and promoted via Sickle Cell Society (and partners') communication channels, featuring questions developed in partnership between the Sickle Cell Society and LAS. A total of 11 people provided written submissions in response.

Please note that all names in the following report have been changed to protect anonymity

INTRODUCTION

As has been outlined in recent reports, including the Sickle Cell Society and All-Party Parliamentary Group on Sickle Cell and Thalassaemia's *No One's Listening*, sickle cell patients have faced decades of under-prioritisation, prejudice and care failings. For many patients and their relatives and carers, these experiences have left them with little faith in the healthcare system as a whole.

In this context, London Ambulance Service (LAS)'s commitment to listening to the experiences of sickle cell patients, and acting on the findings, is particularly welcome. LAS itself has noted that as often the first point of contact for sickle cell patients in crisis, it plays a crucial role in sickle cell patients' experiences of the healthcare system. Contributors to this project echoed this, with one highlighting LAS's important role as "the face of the NHS".

The serious and potentially life-threatening nature of sickle cell disorder means that the importance to sickle cell patients of receiving good quality care from LAS cannot be overstated. Most sickle cell patients have had to call 999 and be attended to by an ambulance, and many of those have to do so frequently. Among contributors to this project, fewer had called 111 – precisely because the seriousness of the condition means 999 and ambulance care is more often required – but some had used the 111 service to seek advice about their condition.

There was a significant proportion of contributors to this project whose experiences with LAS have been largely positive, with some acknowledging improvements in LAS care following past sickle cell patient engagement exercises. For some, this improvement in their interactions with LAS staff was undermined by longer ambulance wait times, which people had experienced as increasing in recent years, particularly since the Covid-19 pandemic.

There were also many, however, who had recent experience of poor care and who raised ongoing issues with how LAS handles their care. Others do not have enough faith in LAS – due to past negative experiences or because of experiences their peers have had – to use its services. Changes to LAS services and meaningful engagement with the sickle cell community to communicate these changes are essential to ensure all sickle cell patients feel confident they will receive the care they need from LAS.

While this engagement should be ongoing, many contributors also told us that this must be the last time a significant consultation exercise is required – because this would mean that changes arising from this project have successfully addressed the needs of the sickle cell community. The Sickle Cell Society welcomes LAS's instigation of this exercise and its commitment to working with the Society and the wider sickle cell community to improve the care it provides.

TESTIMONY FROM THE SICKLE CELL COMMUNITY

Over the course of this project, a number of key themes emerged from the testimony of the sickle cell community. Below, the insights provided by participants in the project are outlined under these themes.

Positive experiences with London Ambulance Service

The remainder of this report outline issues the sickle cell community raised as requiring consideration by London Ambulance Service (LAS), many of which relate to previous negative experiences with LAS. However, it is important to first acknowledge that there were also a significant number of contributors who reported having had positive experiences with LAS.

A number of contributors told us that they felt their experience with LAS had improved in recent years. Claire and Peter, both parents to young adults with sickle cell, said that "the London Ambulance Service has improved significantly over the last 10 years". While caveating that care for sickle cell patients is still too often inconsistent, they acknowledged that "a lot of work has been invested in ensuring [LAS] tries to accommodate the needs of those with sickle cell disorder."

It was noted that previous work by LAS to engage with the sickle cell community had led to some improvements, with one contributor involved with the London Ambulance Service Patients' Forum saying that subsequent surveys had suggested "substantial" improvements had been made to sickle cell care.

Zara, who had a positive experience of receiving care from LAS during the Covid-19 pandemic, felt that her good care may have been due to the increasing awareness at that time of "some of the inequalities and disparities" faced by people with specific conditions, such as sickle cell. As a result, she felt "there was quite a lot of understanding and awareness about treating it properly and what to do and what not to do".

Sickle cell professionals interviewed as part of the project also said that their understanding from patients was that their experience with LAS had improved over time. Gillian, a specialist sickle cell nurse at a hospital in north-east London, said that her impression is that there is more understanding, more assistance with helping with pain and less judgement than in the past.

> "There was quite a lot of understanding and awareness about treating (sickle cell) properly and what to do and what not to do"

The positive experiences that were recounted are instructive in understanding what constitutes good care for sickle cell patients from LAS.

Clear and compassionate communication from LAS staff was stressed as being an important factor by those reporting positive experiences. Kemi described interactions with LAS staff where they "asked relevant questions, [were] very calm, and clear and concise in communication".

Describing a positive experience, Zara noted that LAS staff were "respectful" and "kind" in their interactions with her. Jane noted that delays in the ambulance arriving were often an issue she faced, but that "once the crew have got to me, it's always compassionate, it's always caring. I haven't had a negative experience of any crew".

Others highlighted being provided with **appropriate pain relief** and **other supportive measures** as being important factors in their positive experience with LAS. Cherelle told us she was provided with Entonox and some morphine, as well as a wheelchair to help with transportation, which helped to make her experience with LAS "very good". Jane noted that she is normally provided with a stretcher or wheelchair and Entonox, and that she has also been assisted in being wrapped up to protect against cold weather conditions, which can instigate and exacerbate sickle crises.

Being offered the **choice of which hospital to be taken to** was also mentioned as contributing to positive experiences with LAS. Felicity described being proactively asked which hospital she wanted to attend, which she had been previously unaware was something patients were able to have a say in.

Another contributing factor to positive experiences was LAS staff playing an **active role in handover to the hospital**. Zara said that an ambulance crew that attended to her called ahead to the hospital they were taking her to, which meant a room was already prepared for her when she arrived.

The ambulance crew came into the hospital with her to make sure she had everything she needed, which she said meant "the handoff was brilliant". Similarly, Felicity told us about her experience where an ambulance crew came into the Emergency Department with her, checked her in and waited for a while to ensure that a hospital clinician was going to attend to her.

Listening to patients and **being open to learning more about the condition** are both key. For example, Claire, a mother of a young sickle cell patient told us about a time when her son had had to undergo a hip replacement and, due to complications, was transferred between hospitals by ambulance. She told us that "he felt that the ambulance staff did listen to him" about his sickle cell condition and that, as they had not previously provided support to a sickle cell patient, "they were definitely open to learn, and appeared to want to know more". During the transfer, he was asked what assistance he needed. As a result of the above, Claire characterised the LAS staff members' approach as having been "caring and sensitive to all [his] needs".

Likewise, Zara described being "really impressed" by LAS paramedics who had said to her, "We don't know a lot about sickle cell, but what we do know is we should just listen to the patients and be guided by what you want". Zara told us, "I just really appreciated that, them acknowledging that they might not be the experts in the room, but actually just work with the patient to be able to support them".

Avoiding ambulance care

By contrast to the positive experiences above, there were a number of contributors who told us that they actively avoid seeking ambulance care. Often, this was due to past negative experiences with LAS, or having heard of negative experiences from other sickle cell patients.

A joint written submission from four individuals (one sickle cell patient, two parents of young adults with sickle cell, and one widow of a sickle cell patient), who had also sought the views of peers, stated: “There is a general consensus that the majority of people spoken to are very reluctant to call the ambulance service unless it is the only and last resort and the pain is so bad they have no excuse but to go hospital. This is for numerous reasons: fear of not receiving appropriate pain medication en route, not being listened to in terms of what their needs are and perception of being seen as a drug seeking individual.”

They added that sickle cell patients’ views of LAS were often “marred by past performance”, with one carer they spoke to recalling “numerous times that her husband refused to call LAS as he felt they would take too long and they wouldn’t address his needs”.

Sherelle, a parent to a child with sickle cell, described an experience of having an ambulance attend for her child ten years ago, where they felt they were not listened to or prioritised appropriately. Due to this, and having “heard of several disasters when using the service”, she said “the ambulance service would not be my first choice if help was needed” and she “wouldn’t want to chance it, especially if time is of the essence in getting medical attention”.

Others said they would prefer to rely on taxis or Ubers to get to hospital. Harriet told us that an incident in which she had called an ambulance for her mother and felt dismissed meant that she would prefer to rely on Uber. Sarah said that she would call Uber “because I feel safer in the Uber, and I know I will get to the hospital much sooner in an Uber ... Hearing other sickle cell patients’ negative LAS experiences does not fill me with confidence in the system”.

Iyanla said she stopped calling ambulances around 2017 due to hearing a lot about others’ negative experiences. She told us that she calls an Uber, or a friend, or tries to get the bus and even, on one occasion, “psyched herself up” into driving herself to the hospital, a patently undesirable course of action for someone experiencing a sickle crisis.

Jenny said that past “mistreatment” meant that she would rather rely on friends and family to take her to the hospital when she has a sickle crisis during the day. If she has a flare-up at night, she will often try to wait it out until morning but often ends up relenting and having to call an ambulance.

These experiences demonstrate the absence of trust some sickle cell patients have for LAS, which must be restored to ensure they are able to feel confident in accessing LAS care. LAS should consider how it can effectively communicate to sickle cell patients about changes it has made to improve their care to provide this reassurance.

Inconsistent of treatment

A number of contributors raised the inconsistency of care received from LAS, which prevents some sickle cell patients from having the confidence of knowing they will receive good care when they need to use LAS.

Claire and Peter, both parents to young adults with sickle cell, said that, despite improvements over time in LAS care for sickle cell patients, “there remains a widespread inconsistency depending on the crew that arrives.”

Another parent of a sickle cell patient said the same, noting that they had used 999 and ambulance services three times in the previous four months and that: “It feels like pot luck every time. There is no consistency in their understanding of the condition ... It is hit and miss and depends on the crew you get”.

> “It feels like pot luck every time. There is no consistency in their understanding of the condition ... It is hit and miss and depends on the crew you get”

Jenny, who had recounted examples of being treated with scepticism and refused pain relief and mobility assistance, said she felt LAS staff are “fifty-fifty”, sometimes believing she’s in the level of pain she tells them she’s in, and sometimes not. Another sickle cell patient, Ellie, said “sometimes, you get people who are okay, and sometimes I’ve got people who are a bit challenging ... Some of them will have the knowledge about [sickle cell]. Some will give morphine, as well, but some of them wouldn’t offer morphine”.

Zara outlined her view that care failings in secondary care settings are due to “structural inequalities that mean that you probably do have more consistent problems because they’re the same kind of structural issues wherever you go”. By contrast, she felt the inconsistency of care from LAS was “due to humans” and that this demonstrates the importance of education and training around sickle cell, to reduce the variance in treatment.

Consistency of treatment is an important factor in sickle cell patients’ confidence in the service they receive from LAS. The examples outlined above, where the same patients have experienced wildly varying treatment, demonstrate the importance of comprehensive, ongoing training that ensures LAS staff provide consistent treatment to sickle cell patients.

Experiences of care failings

A number of contributors to the project told us of examples of care failings they had experienced from LAS.

Caroline, a mother of a child with sickle cell, told us about an ambulance attending to her son in March 2024, during which the ambulance crew "[made] my son walk, even though he is in a crisis" and "did not talk or check on my son during the entire journey". Despite the risk of cold exacerbating a sickle crisis, she told us "they left the ambulance door open [and] did not offer a blanket", nor did they offer oxygen. She has experienced ambulance crews with poor knowledge of the condition, with some asking, "How long has he had sickle cell?" Caroline added, "Surely they are trained to know it is a genetic condition. When we hear this (which is often), I lose all hope of anyone understanding the pain my child is experiencing."

A lack of physical support for getting to the ambulance was also mentioned by others. Marsha, a mother of a teenager with sickle cell, told us of a similar recent experience to Caroline's, where an ambulance crew had expected her son to walk to the ambulance. In the end, she told us that his father and brother carried him to the ambulance due to the lack of assistance.

Jenny, a sickle cell patient, said she normally has to ask for a chair to transport her to the ambulance and that it is then fifty-fifty whether she is provided with one, meaning there have been several occasions where she has had to endure a "painful walk to the ambulance". She told us that on one occasion she was told that she did not need a chair because she had been able to get to her front door to let the ambulance crew in, which did not recognise the difficulty she had faced in doing so.

While it should be noted that the incident took place a few years ago, Fatima also told us that she had been attended to by an ambulance crew, who "asked me to stand up and walk a couple of feet to see if I'm fit enough for a chair, or if I can walk to the ambulance". This was despite the fact that Fatima "couldn't even get out of bed because my legs were in so much pain".

Fisayo said that while she normally has been offered a stretcher or a carry chair by paramedics, she has not been provided with other required support. She said "there appears to be a lack of knowledge and understanding [of] how cold weather exacerbates and/or triggers painful episodes. Paramedics have sometimes neglected the need to ensure I am sufficiently warm, especially if my crisis has occurred in the winter or at night (which is most of the time). As such, I have had to request blankets, which is physically necessary, but mentally draining and adds to distress when in acute pain."

> **"How long has he had sickle cell?"**
> "Surely they are trained to know it is a genetic condition. When we hear this (which is often), I lose all hope of anyone understanding the pain my child is experiencing."

One example of a significant care failing we were told about was from Jenny, who highlighted an occasion in which an ambulance crew had not believed that she was undergoing a sickle crisis and had refused to provide pain relief. They had instead told her that they believed she was having a panic attack and even informed Emergency Department staff upon arrival that they thought she was having a panic attack. Jenny said that she then had to muster the energy to speak up and say that she was actually having a sickle crisis; by the time she was properly attended to, the ambulance staff had left, meaning they were not present to have their misconception disproved.

Kelvin, who had been involved in previous clinical audits undertaken by LAS, noted that "nobody should expect a sickle cell patient to walk to an ambulance, there's guidance on this. Nobody should expect a patient not to receive pain relief". He questioned whether this meant that LAS staff were not receiving sufficient training to understand how they needed to respond to sickle cell patients.

We also heard from one patient who felt that 111 call-handlers had failed to recognise the seriousness of her condition, which had then led to hospital admission. She told us: "I don't think they've been as responsive [as 999 call-handlers]. They've maybe turned questions round to me and said, 'Oh, well, do you think you need to go into hospital, or do you think you need an ambulance?' I don't think that's too helpful because I'm asking them what they think needs to happen to me! Then I've had to go into A&E or get someone to take me, and have ended up in hospital, subsequently, from that."

There are lessons to be drawn from these experiences of care failings. Training for LAS staff should ensure that they possess a basic understanding of the sickle cell disorder condition and understand the importance of providing supportive measures – such as pain relief, mobility assistance and protection against cold – as a matter of course for those experiencing a sickle crisis.

Lack of appropriate pain relief

A specific example of a care failing that was repeatedly raised was patients not being given access to appropriate pain relief by LAS.

We were told of a patient suffering chest pain as a result of a sickle crisis, and yet only being offered Entonox, despite her telling us she "clearly need[ed] something stronger". Similarly, Caroline said of the ambulance crew that attended to her child that "there appeared to be confusion over what should be offered" and that they "were reluctant to give morphine".

Fatima told us she has to rely on Entonox as she is allergic to morphine, yet had an incident in 2022 where she was not even given this because "they thought I was addicted to Entonox, so they said they wouldn't give it to me because I'm addicted, so I had to get out of [the ambulance], get a taxi, and go to the hospital". This failure to provide appropriate pain relief due to stigmatising attitudes was a particularly egregious example of a care failing.

Others said that they had been provided with pain relief but noted that the limits on how much LAS staff are able to administer present issues. Olivia, for example, told us: "The paramedics I've encountered are very caring and knowledgeable about sickle cell, understanding the pain and the need for painkillers. However, they have to follow specific protocols. For example, they weren't allowed to administer morphine or strong painkillers and had to use gas and air, which didn't help much … The paramedics were very supportive, but they were limited by the system's protocols."

Fisayo's comments were also echoed by Dianne, who said "I've always been treated well and offered what they can, but they've had issues … with the [pain relief] supplies they have". Paul added that LAS staff he has encountered are "knowledgeable, understanding, and helpful" but "there are limits to what they can do" when it comes to administering morphine.

We received recommendations on how service protocols could be reconfigured to improve pain relief. Claire, mother to an adult sickle cell patient, said that pain relief that has been administered by LAS staff should not be counted toward meeting the NICE clinical guideline that sickle cell patients should receive pain relief within 30 minutes of presenting at hospital, given the level of pain relief is often insufficient to meet their needs. She wrote: "At handover the ambulance staff should specify what time analgesia was given and if the person is still in pain the handover should state so and maybe encourage ED staff to administer analgesia as a matter of urgency".

Separately, Zara said that consideration should be given to ambulances being able to offer more pain relief. She told us: "The main reason why you would call an ambulance [for sickle cell] is because you're in severe pain. If the ambulances can't administer the drugs according to your care plan, even if they had access to it, there's nothing really they can do … unless something else changes about what they can and can't do, I don't know how impactful [having access to patients' care plans] will be anyway."

It is crucial that LAS staff training challenges stigmatising attitudes towards sickle cell patients that can result in the perpetuation of 'drug seeking' narratives which mean patients do not receive the pain relief they need. The restrictions on how much pain relief paramedics are able to administer is also a key issue for sickle cell patients. LAS should consider engaging with NHS England and the Commission on Human Medicines around the potential reconfiguration of service protocols on administering pain relief.

"Attending paramedics have been aware of the urgent need to alleviate my pain promptly [but] they have often been limited in their ability to achieve optimal pain control".

Testimony from the sickle cell community

Difficulty of answering lots of questions during a sickle crisis

Another common contribution from participants was a feeling that they are asked an excessive amount of questions by LAS while undergoing a sickle crisis, and that they do not all seem relevant.

One patient, Jenny, said that when calling 999, "you're in pain and agony, yet then there's millions of questions on the phone". She said that in her view the number of questions should be reduced and that when a call handler hears the words 'sickle cell', the only follow-up that should be required is to ask for the address and then dispatch an ambulance. Currently, she relies on the workaround of calling a friend when she is having a sickle crisis, who then calls the ambulance for her, because Jenny is incapable of answering the number of questions 999 call-handlers ask when in that much pain.

Another patient, Abeni, said the same of 111. Having called it once before, she told us, "I don't think it's a service I would ever use again when I have a severe crisis, mainly because we get unnecessary questions. For me, personally, when I'm having my crisis and it's really bad, speaking is the last thing I want to do. I just want that medication."

Even Claire, the mother of a sickle cell patient who cited paramedics' openness to learning more about the condition as a positive (as outlined above), noted that there is a negative side to that too. She noted that when "you don't feel well and are doubled up in pain it is difficult to try to explain to someone about your condition" and that her son had said, "You just want them to get rid of the pain … as opposed to teach[ing] and train[ing] people".

Others argued that some of the questions asked by call-handlers do not seem relevant to a sickle crisis. For example, Leanne said: "They ask you all these questions, which I also don't think is relevant to sickle cell. Obviously, they have this protocol they have to go through when they speak to everybody, but a lot of the questions are irrelevant to someone that's suffering from a crisis. When you already lack oxygen, and you can't breathe, I felt like it was just a lot of wasting time". Similarly, Zara told us "not all of the triaging questions are that relevant to your condition".

While there was some recognition and understanding among some sickle cell patients that LAS call-handlers have specific protocols they must adhere to, the number of contributors who highlighted facing too many questions during a sickle crisis shows that this is a key issue for sickle cell patients. LAS, in partnership with the Sickle Cell Society and NHS England, should engage with the sickle cell community around its protocols on call-handler questions and seek to identify opportunities to reduce the number required for people experiencing a sickle crisis.

Not feeling listened to or respected

Some participants told us about times in which they had felt that they had not been listened to or respected by LAS staff.

Sherelle provided us with an example from ten years ago when she had to call an ambulance for her son. She said when the paramedics arrived at her home she tried to explain the situation calmly "even though I was frantic" but "I did not feel listened to" and "there was no sense of urgency".

More recently, Jenny told us that she has had experiences with paramedics where she has felt she is being treated as if she is being "difficult" for not being able to walk and that it is implied she does not want to get in the ambulance.

Jasmine shared an experience where she had to get an ambulance out at a time when she had people in her home to celebrate her birthday. When the paramedics arrived, they questioned why someone there had not been able to take her to hospital. This failed to respect the importance of care being available during transfer to the hospital.

Ifelayo said that she felt disrespected when calling 999 as a sickle cell patient in the past. Now, to avoid "being categorised as a [drug] seeker", she said that she does not mention sickle cell when calling for an ambulance – instead, she will mention chest pain and being unable to breathe properly. This means that "in less than five minutes they're in the house" because she is afforded more respect and prioritisation.

Felicity, who was among those who reported generally positive experiences with LAS, did note that she had called 111 a couple of years ago and characterised the call-handler's response as, "Are you really having a sickle crisis?" As such, she said, "999 versus 111, it'd be 999 all the time".

A number of contributors felt that their condition is taken more seriously when it has already been recognised by another healthcare professional, and that this demonstrates a lack of respect for sickle cell patients. For example, participants in one of the focus groups agreed that their experience of ambulances is more positive during hospital-to-hospital transfer than being taken from their home to hospital, and that this may be because the seriousness of the situation has already been 'legitimised'. Another patient said that recently she has taken to calling a specialist sickle cell nurse to get her assistance in getting an ambulance, because she feels that this is more likely to ensure the seriousness is recognised.

Reflecting on this, Zara said that "patients should be seen as a credible source as well. I think that the health system probably sees a clinical referral as a more credible source of urgency than a patient that calls up" and this means "they don't get the help that they deserve if they don't have someone to advocate on their behalf".

Sickle cell patients are experts in their condition and should be respected as such by all LAS staff. Training should ensure that LAS staff understand the importance of listening to sickle cell patients' needs and providing mobility assistance and pain relief to sickle cell patients as required.

> "Even though I was frantic, I did not feel listened to ... there was no sense of urgency".

Insufficient priority and slow attendance

A significant number of participants highlighted issues with how quickly they were attended to by LAS.

For some, their experience of being attended to slowly may have reflected general pressures on LAS's ability to meet optimal response times, rather than being anything specific to sickle cell. For example, Jane told us of a negative experience around eight or nine years ago where she had called 999 a few days before Christmas. She was informed that an ambulance would be with her in around 30 minutes. However, after four hours she had still not been attended to. She went on, "At the time, I was living in my flat by myself, so had no relatives with me, which was obviously a very vulnerable time ... [After four hours had passed] I needed to call my brother, who lived not too far away and picked me up, put me in a taxi and took me to A&E". Once there, it was revealed she "had an acute chest syndrome, which is quite significant and life-threatening if you don't get access to really rapid care".

Based on this and other experiences, Jane told us that it is waiting times that are the negative aspect of her experiences with LAS, saying: "Once I'm in the care of the crew, it's been great ... they've done a good job in terms of that compassion and care, and keeping me safe. It's the prior [part], it's getting the crew to come to you that is the main problem from my perspective."

A number of patients felt that waiting times had increased in recent years, particularly following the pandemic. Iyanla said that attendance times were better in the mid-2000s and were still "alright" when she last called an ambulance in 2019. However, she said that her interactions with other patients had suggested waiting times had increased since the pandemic, with people experiencing three hour waits or longer. This has led her to decide that it is not worth trying to call an ambulance. Likewise, Leanne said that she "had more good experiences pre-Covid" but "a lot of my experiences have deteriorated after Covid" and she would now "usually avoid calling an ambulance".

Abeni also felt that waiting times have increased recently, saying that "even up until a couple of years ago, the ambulance service response was quite good for us" but that "as the service is impacted with funding, things changed" and waiting times have gone up.

Others felt that delays were not just reflective of wider challenges facing LAS, but because sickle cell patients do not receive sufficient prioritisation. Sarah told us about having to call an ambulance for her sister, who also has sickle cell disorder, and being informed it could take anywhere from 40 minutes onwards before they would arrive. She said her sister "was in so much pain, and I was exceptionally worried about her. Just when I was about to order an Uber, LAS arrived. The staff were nice; however, I felt like they were not moving fast enough".

Leanne recounted an experience of calling an ambulance in December 2022 during a period where ambulance service staff were taking strike action. When Leanne called, she was informed that they were only coming out to Category One patients and "right now, I'm not priority". She added: "To me, I was having a very bad chest crisis ... I've had other chest crises, but that one was the most severe I felt all day, and I really, really needed urgency. I felt like urgency is what they lacked when I needed to come in. If it wasn't for the fact that I had a friend that lived 20 minutes down the road, to communicate on my behalf, I don't think I would have made it."

Paul also felt that sickle cell patients are not always sufficiently prioritised by 999 and 111 call-handlers. He said that "nine out of ten times, explaining my situation results in an OK response. Yet, I have experienced long waits, sometimes several hours". He argued that "education is crucial" to ensure that LAS staff "understand that sickle cell crises are life-threatening and require urgent attention".

Some contributors had the impression that a sickle crisis is categorised by LAS as requiring less urgency than heart attacks or strokes. In actuality, all are Category Two incidents, which means they are all classed as 'emergency calls' and, under LAS targets, should be responded to in an average time of 18 minutes. This points to a role for LAS in better communicating its categorisation system to the sickle cell community.

Many sickle cell patients feel that the response they receive from LAS does not reflect the seriousness of their condition. LAS guidance, training and reviews for its staff should ensure that all call-handlers and clinicians respond to a sickle crisis with the same level of urgency as they would for other Category Two incidents, such as suspected heart attacks and strokes.

LAS should work with the Sickle Cell Society to develop communication to the sickle cell community about its categorisation system, to improve understanding of the level of prioritisation accorded to sickle crises by LAS.

> "To me, I was having a very bad chest crisis ... I've had other chest crises, but that one was the most severe I felt all day, and I really, really needed urgency. I felt like urgency is what they lacked when I needed to come in. If it wasn't for the fact that I had a friend that lived 20 minutes down the road, to communicate on my behalf, I don't think I would have made it."

Use of care plans

Some participants provided their perspective on how well LAS takes into account and makes use of sickle cell patients' care plans.

Atara said that she has a care plan and that it is largely, but not always adhered to. She said: "I do have a care plan and 90 per cent of the time they do follow it, and they do give me the pain relief that's on my care plan". However, she added, "There have been a few occasions where they've been a bit nervous to give me the pain relief, maybe because of what I've had during the day [before calling the ambulance]", meaning they do not follow what is in the care plan.

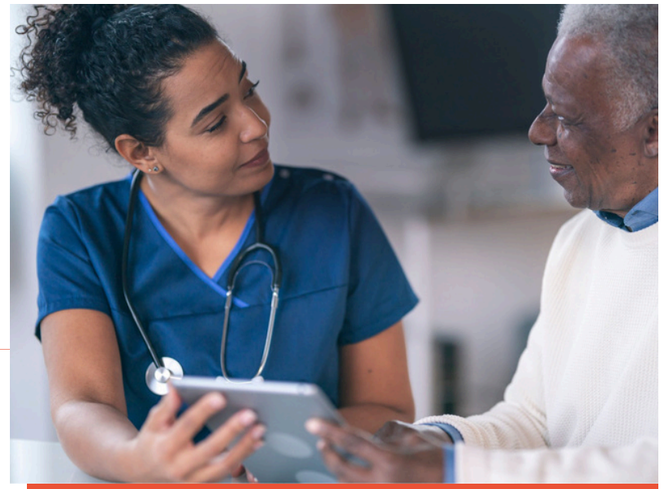
Zara raised questions about the extent to which LAS staff are able to access and make use of sickle cell care plans. She said that on an occasion where she had used LAS services, the ambulance staff "didn't really have access to the care plan".

Before getting the ambulance, she had called 111 and was told by the GP she spoke to that "they have no real insight into the care plan. They have very basic high-level stuff and that's it. So there was a point where I had to explain a little bit more about 'this is what I would normally do and this is the care plan and everything', and I think that's why he then said, 'You know what, the rest of this care plan has to be administered in hospital rather than at home.'"

Others had uncertainty about the ongoing roll-out of Universal Care Plans (UCPs) in London. Harriet questioned how much training LAS staff will receive on UCPs so that they are utilised, noting that sickle cell patients want to know that they "won't be ignored, that they will be genuinely taken into account and not questioned".

Similarly, Felicity did not yet have a care plan and wanted to know whose responsibility it will be to ensure sickle cell patients understand how they can make use of their care plan, including ways they would be able to present their care plan to paramedics if they cannot speak or are struggling to breathe. She said: "This conversation needs to happen so that patients are aware and can use their care plans effectively during emergencies".

This testimony again suggests LAS should prioritise communication to the sickle cell community to provide reassurance around how its staff will utilise sickle cell UCPs, and to ensure patients themselves have the information they need about how UCPs will work.



Testimony from the sickle cell community

Not being taken to preferred hospital

A number of different participants cited not being taken to their preferred hospital as a negative factor in their experience with LAS. This is an issue relevant to many sickle cell patients, given many attend a specialist hospital for their sickle cell care that is not their local hospital.

Following NHS England's Haemoglobinopathy Service Review in 2018-19, a new approach to sickle cell services was instituted, with the formation of Specialist Haemoglobinopathies Teams and regional Haemoglobinopathy Coordinating Centres (HCCs). This recognised that some NHS Trusts had particularly well-developed expertise in providing sickle cell care. The aim of establishing HCCs was to develop a system-wide networked approach that ensures these specialist centres support other hospitals with less expertise, to ensure a consistent and good standard of sickle cell care in all hospitals.

However, with this approach to services only instituted in 2020 and many non-specialist hospitals still under-resourced (including for specialist sickle cell nurse roles, as outlined in the Sickle Cell Society's *The Difference Between Life and Death* report), specialist centres are still often better-equipped to provide a high standard of sickle cell care.

We heard from a number of patients that their local hospital is not equipped to provide them with the care that they need, and that being taken there will often mean that they subsequently have to transfer to their specialist centre.

Caroline, mother of a child with sickle cell, said that she and her family often face objections from paramedics when they ask to be taken to their specialist centre, King's College Hospital, instead of their local hospital, where she told us her son "has frequently been let down when having a crisis". She said that on one occasion, "the ambulance team refused to take us to King's, [so] we drove in the car and took him to King's ourselves".

Fatima had the same issue – she told us that her specialist centre is St. Thomas' Hospital in central London but she does not live nearby and has repeatedly faced issues with ambulance crews saying the distance is too far to take her to St. Thomas'. She said: "My doctors, they've written letters. I have a care plan with me. I have the sickle cell card with me, and I have to be taken to St Thomas'. So my issue has always been the argument between the ambulance crew and the control team. The ambulance crew will argue with me, argue with my husband, my family, and then it will take about 45 minutes. Then they will decide to call control and control will tell them, 'Take her to St Thomas'.' So why does it have to be that 45 minutes' argument before they agree? I could have been on my way to St Thomas' by that time."

Similarly, Zara told us "there is no point you taking me to [my local hospital] when they don't have the speciality and they don't have my care records. They don't have my care plan. They have no idea who I am or how to deal with me and my history, all that kind of stuff. At the end of the day, if you're going to take me there, I will have to try and find my way to [my specialist hospital] at some point, and it's probably going to be dangerous, and also it's going to be wasting time, it's going to be frustrating, it's just going to ruin the entire experience".

Zara told us that thought should be given to changing the guidelines to enable some more flexibility in where people are taken by LAS. While she acknowledged that there is not always the capacity for ambulances to make long journeys, she suggested a reasonable solution may be for LAS guidelines to state that sickle cell patients should only ever be taken to a specialist sickle cell hospital, where they have a haematologist available 24/7, "rather than taking them to a place where there's no real expertise around sickle cell, and they're not best equipped".

This view from patients and carers was also supported by specialist sickle cell nurses we spoke to as part of the project. One told us that it "does help patients to go somewhere familiar, where they know the staff" and that it can help with allaying their fears and anxieties. Another said that, a few years ago, she would have said that it's best to take patients to their nearest hospital if they are in acute pain but that now, with such high staff turnover in secondary care, it "probably does make sense to go to a centre where expertise is high".

It is clear that being taken to the nearest hospital is not always appropriate for ensuring sickle cell patients receive the care they need. While contributors acknowledged the challenge LAS faces in ensuring ambulances are available to other patients, a potential compromise is for LAS to ensure its protocols state that sickle cell patients requiring ambulance transfer should always be taken to a hospital that is a specialist sickle cell centre.

> "It does help patients to go somewhere familiar, where they know the staff... it can help with allaying their fears and anxieties."

Testimony from the sickle cell community

Issues with handover to Emergency Departments

Some participants also highlighted issues with handover from LAS to the Emergency Department.

A specialist sickle cell nurse told us that ambulance crews do not do a "proper handover", which means that the severity of the patient's sickle crisis is not adequately conveyed. Another said that they are not even sure what the guidelines are on how ambulance crews are supposed to conduct handover. She said: "We're not sure as professionals what the ambulance crew's procedure is at that point. We're not sure what is supposed to happen. When we hear, 'The ambulance crew just left me there on the chair', I don't know what I should be saying to them."

One of the sickle cell patients we spoke with felt that sometimes ambulance crews abdicate responsibility before knowing that the patient's needs are being met by another healthcare professional. They said sometimes paramedics will drop off a patient and think that "it's not my problem anymore ... that's one of the biggest problems generally with some of our sickle cell care services, I think there's just a lack of accountability and that's why we get so many problems".

Fisayo told us that "care feels sub-optimal in the handover provided to the A&E team. This can be improved via effective communication to staff, explaining the analgesia already taken at home as well as that administered en route. This will help towards the goal of a seamless transition of care, and avoid the individual having to reiterate information repeatedly, which can further add to distress when experiencing a severe crisis". Fisayo said that, where a sickle cell care plan is available, this should be highlighted by paramedics to Emergency Department colleagues, along with details of the pain relief already administered to or taken by the individual.

Ellie told us of an example of her experience that illustrated issues with handover to the Emergency Department. She was taken by ambulance to her local hospital and was finding the Entonox she was provided with by the ambulance crew helpful to managing her pain. She told us the ambulance crew initially accompanied her into the Emergency Department, which she appreciated, but that after a period of waiting to be seen, the ambulance crew told her they would have to leave. She told us, "I said, 'Oh, please, can I continue using this gas I have here? They haven't given me anything yet while I'm waiting in the A&E.' They said, no, they have to go. They basically, more or less, pulled the gas off me. I couldn't believe it ... That was really traumatising for me at that time."

LAS guidance and training for its staff should highlight the importance of a thorough handover to Emergency Departments that ensures effective continuity of care. This should highlight the role that LAS staff can play beyond the minimum operational requirements around handover, such as playing an advocacy role for sickle cell patients – for example, highlighting to secondary care staff the aspects of their care plan that have yet to be acted on.

WHAT LONDON AMBULANCE SERVICE NEEDS TO KNOW ABOUT SICKLE CELL

We asked participants for their views on what they would like LAS to understand about sickle cell – and what it is important for LAS to pass on to their staff in training.

A number of participants wanted LAS to understand that sickle cell is an invisible condition and that patients therefore need to be listened to about what they are experiencing and treated with care regardless.

- "I would like LAS to know that sickle cell disorder is an invisible condition, and each sickle cell patient has their own experience with the condition. One shoe does not fit all."
- "Observation is difficult as you can't necessarily see the pain, someone can have a broken leg ... and [healthcare professionals] are more likely to understand. Yet with sickle cell crisis you can't physically see or understand what is happening".
- "If my arm is not visibly bleeding, it does not mean it does not hurt. Still handle my arm with care and gentleness as with someone who has a visibly bleeding arm."

Many simply wanted to convey the seriousness of a sickle crisis and to say that LAS staff should understand that it is a medical emergency that requires a fast response.

- "Sickle cell is a medical emergency and should be treated and prioritised accordingly."
- "Patients' health can deteriorate in a second and all they've got is the ambulance crew."
- "LAS staff need to know how serious a sickle cell crisis is. They need to know that a crisis is a medical emergency, and each sickle cell crisis has the potential to be life threatening."
- "It's absolutely crucial that the waiting time is met. If it's not, people could literally deteriorate, and harm and death, and all sorts of things, could occur. For me, the recommendation to LAS is just making sure this condition is prioritised as a very serious condition, and clinicians are taking it seriously and understanding the complications that could arise from not responding to care quickly. It could be strokes, it could be heart attacks, it could be sepsis, it could be chest crises, pneumonias, all of which are life-threatening."

Others raised the importance of dispelling stigmatising attitudes about sickle cell patients being 'drug-seekers'.

- "The perception [that leads people] to suggest sickle cell warriors are drug dependent needs to change; sickle cell crisis requires strong drugs that some may be dependent on to control the pain."
- Not all sickle cell patients are drug addicts ... This [accusation] has thankfully, not been my own personal experience, but is often the experience of other sickle cell patients."

We were also told that LAS should be mindful of the fact that accessing their services and being taken to hospital is a last resort for sickle cell patients. This means that they have often been suffering for a while, have tried everything they can and have reached the limit of what they can tolerate.

- "Lots of patients will stay at home for as long as possible because they don't want to go into hospital. They've grown up experiencing pain all their lives and are used to managing it. By the time ambulance comes, they've taken as much as they can tolerate."
- "People do not want to go to hospital, it's not a holiday ... People don't just go to hospital because they want to."
- "My threshold is quite high for me to [get to the point where I] call an ambulance. By the time I have called them, I will be quite visibly unwell".
- "When an individual with sickle cell dials 999, it is a last resort. It takes a lot to make the call, and accept you need help. We have tried everything possible to manage pain at home and without success and as such, we are desperate and in need of care. Therefore, please be kind."

Many told us that an important thing to understand about sickle cell is that people experience pain differently. This means that it should not be assumed that those who appear stoic and contained are not actually in significant pain. It also means that patience and understanding is required when supporting people whose reaction to pain is more expressive.

- "Patients may even come across as impatient, but that's because they're in pain. This is not a moment there's going to be polite exchange, they just need to get to the hospital. Exercise a lot of patience. You know what you're like when you're in pain, you're not yourself ... it's not personal."
- "Some people become very agitated and anxious when they're in pain and when they're ill. I am the complete opposite. I go completely silent. I'm very quiet and very subdued. So actually it's a very non-threatening stance to have. So actually I think it's easier for me to say that I feel confident in the system because, thankfully, I think that the system works with people like me. Whereas, I know that it probably doesn't work for other people."
- "Everyone's pain threshold is not the same. How we all react to pain is different. Sometimes, I feel like when the ambulance comes, unless they see me absolutely visibly distressed, the level of urgency differentiates, whereas the pain is still the same. It's just how much I can handle it at the point in time when they come, or if I've taken painkillers."
- "People react differently. Just because the patient is not screaming, shouting, bawling or reeling around doesn't mean they are not in pain."

Other key messages sickle cell patients had for LAS included:

- "They need to be aware that we are human beings and not numbers. We have been living with sickle cell our whole lives, we are experts in our condition."
- The ambulance service "is the face of the NHS so people want to know they'll receive compassion and care".
- "Sickle cell patients do not always know what is happening when they are having a crisis. For example, when I had a crisis once, I experienced numbing in my face, which I thought was a stroke at the time. Sickle cell crisis can also present other symptoms that the patient does not understand."

CONCLUSION

The testimony provided by contributors to this project reveal that there are a significant number of sickle cell patients with positive experiences with London Ambulance Service. The evidence also suggests that there have been improvements in the care sickle cell patients receive from LAS in recent years. This includes greater awareness of the condition among LAS clinicians and better provision of best-practice care. This positive trajectory is encouraging and is something for LAS to build on in the coming years.

However, we also heard from many patients who have had negative experiences – some historic, some recent – with LAS, which have affected their confidence in the service. Some of the key themes of those who detailed negative experiences include lack of appropriate pain relief, inconsistent care, having to answer too many questions while in acute pain, not feeling listened to or respected, insufficient priority and slow attendance, not being taken to a preferred hospital and issues with handover from LAS to Emergency Departments.

Ensuring that LAS continues its progress in addressing the concerns of the sickle cell community will require acting on the recommendations outlined in this report. It will also be crucial for LAS to engage in ongoing communication with the sickle cell community around the actions it is taking. The Sickle Cell Society looks forward to continuing to work closely with LAS to facilitate this ongoing engagement.

RECOMMENDATIONS

Recommendation: London Ambulance Service to routinely involve sickle cell patients in training for its staff, whose lived experience testimony can help to convey the seriousness and impact of living with sickle cell.

Recommendation: London Ambulance Service to reflect on the key factors cited by those who reported positive experiences with LAS and consider how this good practice can be embedded in all LAS care for sickle cell patients (e.g. through training, guidance and clinical audits). These factors include:

- Listening to patients and being open to learning more about the condition.
- Clear and compassionate communication.
- Providing appropriate pain relief and other supportive measures.
- Offering the choice of which hospital to be taken to.
- Playing an active role in handover to the hospital.

Recommendation: London Ambulance Service training to ensure that staff have a basic understanding of the sickle cell disorder condition, including that it is a genetic condition and that a sickle crisis can be life threatening (as per NICE guidance), and should challenge stigmatising attitudes.

Recommendation: London Ambulance Service to use training and clinical audit-informed performance reviews to ensure that all LAS paramedics provide supportive measures – such as pain relief and mobility assistance – as a matter of course for those experiencing a sickle crisis.

Recommendation: London Ambulance Service to work with the Sickle Cell Society to develop educational communication to the sickle cell community about sickle cell Universal Care Plans and how they will be utilised by LAS.

Recommendation: London Ambulance Service to engage with NHS England and the Commission on Human Medicines around the potential reconfiguration of service protocols that limit how much pain relief can be administered by paramedics to sickle cell patients.

Recommendation: London Ambulance Service, in partnership with the Sickle Cell Society and NHS England, to engage with the sickle cell community around its protocols on call-handler questions and seek to identify opportunities to reduce the number required for people experiencing a sickle crisis.

Recommendation: London Ambulance Service to work with the Sickle Cell Society to communicate to the sickle cell community about changes it has made to improve care, to contribute to restoring the trust of those who avoid using its services due to past negative experiences or negative feedback from peers.

Recommendation: London Ambulance Service guidance and training for its staff to highlight the importance of a thorough handover to Emergency Departments that ensures effective continuity of care. This should highlight the role that LAS staff can play beyond the minimum operational requirements around handover, such as playing an advocacy role for sickle cell patients.

Recommendation: London Ambulance Service to share a copy of this report with NHS England, the All-Party Parliamentary Group on Sickle Cell and Thalassaemia and all four London Haemoglobinopathy Coordinating Centres and establish ongoing partnership working with these key stakeholders.

Recommendation: London Ambulance Service, in partnership with the sickle cell community, to review the metrics used in clinical audits for sickle cell care to ensure they are reflective of sickle cell patients' needs, including protection against cold.

Recommendation: London Ambulance Service to work with the Sickle Cell Society to communicate to the sickle cell community about changes it has made to improve care, to contribute to restoring the trust of those who avoid using its services due to past negative experiences or negative feedback from peers.

Recommendation: London Ambulance Service to work with the Sickle Cell Society to develop communication to the sickle cell community about its categorisation system, to improve understanding of the level of prioritisation accorded to sickle crises by London Ambulance Service.

Recommendation: London Ambulance Service guidance, training and reviews for its staff to ensure that all call-handlers and clinicians respond to a sickle crisis with the same level of urgency as they would for other Category Two incidents, such as suspected heart attacks and strokes.

Recommendation: London Ambulance Service to work with the Sickle Cell Society to undertake ongoing engagement with the sickle cell community on changes being implemented following this project, and continue to utilise communication opportunities such as World Sickle Cell Day each year.

Recommendation: London Ambulance Service to update its protocols to state that sickle cell patients requiring ambulance transfer should always be taken to a hospital that is a specialist sickle cell centre.

Annex