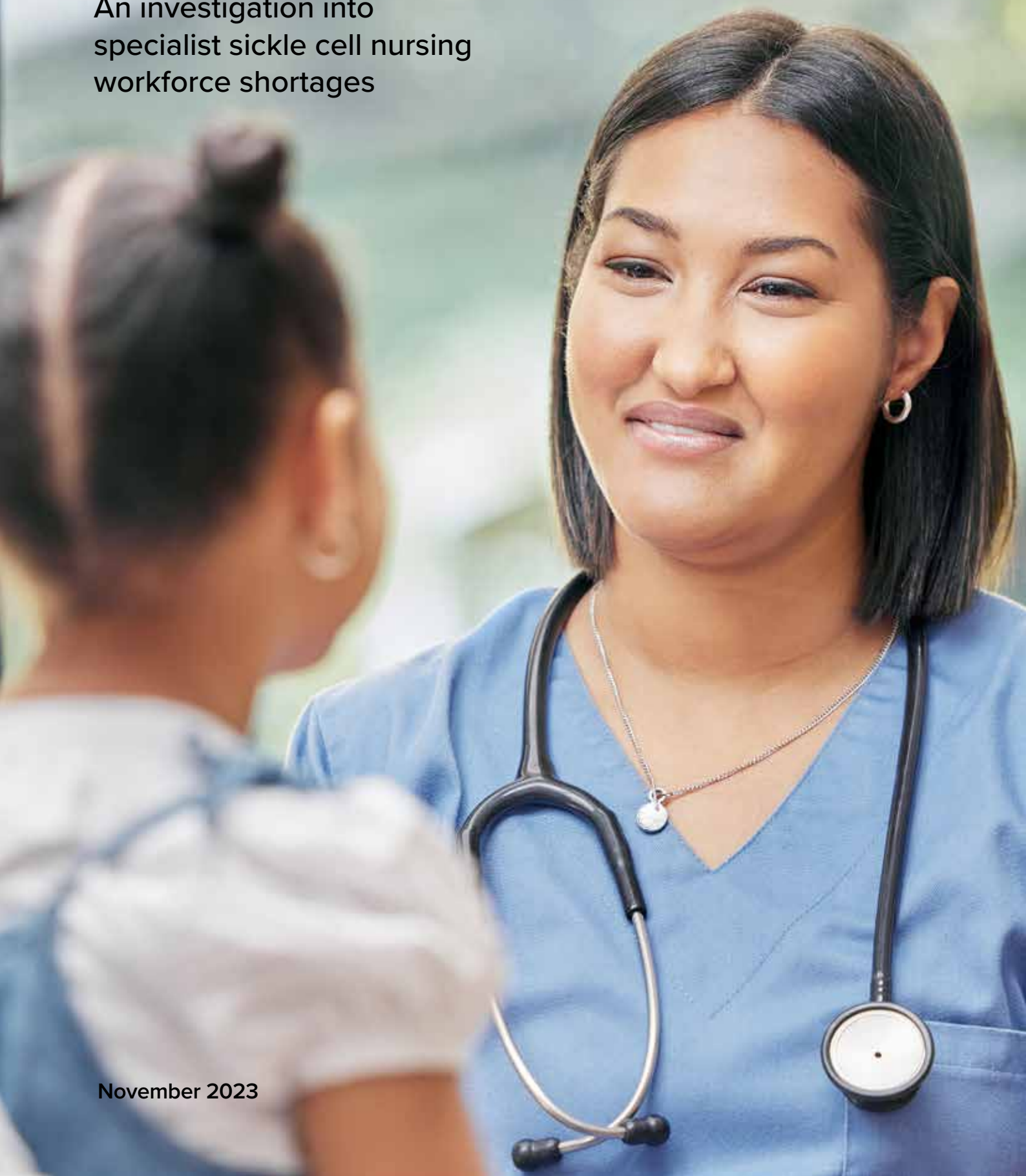




SICKLE
CELL
SOCIETY

'THE DIFFERENCE BETWEEN LIFE AND DEATH'

An investigation into
specialist sickle cell nursing
workforce shortages



November 2023

CONTENTS

FOREWORD	4
EXECUTIVE SUMMARY	6
– What do specialist sickle cell nurses do and how does it benefit patients?	7
– Is the specialist sickle cell nursing workforce level sufficient?	7
– Impact of specialist sickle cell nursing workforce shortages	7
– Why are there too few specialist sickle cell nurses?	8
– What needs to happen to address the specialist sickle cell nursing workforce shortage?	8
INTRODUCTION	10
METHODOLOGY	11
WHAT DO SPECIALIST SICKLE CELL NURSES DO AND HOW DOES IT BENEFIT PATIENTS?	12
– Clinical care and support	12
– Social support	14
– Benefit to patients	15
IS THE SPECIALIST SICKLE CELL NURSING WORKFORCE LEVEL SUFFICIENT?	16
– The current situation	16
– Community nursing and nurse counselling	19
– Regional variation	21
– Disproportionate understaffing in sickle cell services	23
– Expectations for the future	24

WHAT IS THE IMPACT OF SPECIALIST SICKLE CELL NURSING WORKFORCE SHORTAGES?	26
– Impact on patients and carers	26
– Impact on clinicians and the care they provide	30
WHY ARE THERE TOO FEW SPECIALIST SICKLE CELL NURSES?	32
– Funding and lack of prioritisation by healthcare leaders	32
– Perceptions of sickle cell as an undesirable specialism	33
– Insufficient training and experience in sickle cell	34
– Lack of opportunity for career progression and unclear career pathways	35
WHAT NEEDS TO HAPPEN TO ADDRESS THE SPECIALIST SICKLE CELL NURSING WORKFORCE SHORTAGE?	36
– Defining and mandating a minimum specialist nurse/patient ratio	36
– Increasing and making best use of funding for sickle cell services	38
– Increasing sickle cell training and experience	40
– Ensuring greater opportunity for progression	41
– Increasing collaboration and forums for mutual support	42
– Adopting measures to increase specialist sickle cell nurses’ capacity	43
CONCLUSION	45
APPENDIX	46

FOREWORD

In 2021, the All-Party Parliamentary Group (APPG) on Sickle Cell and Thalassaemia, supported by the Sickle Cell Society, conducted an inquiry into sickle cell care in secondary care services.

Among the key findings of the subsequent report, *No One's Listening*, was that inadequate staffing levels for sickle cell care are a key factor in the care failings sickle cell patients encounter. The inquiry was told of “chronic under-staffing”, with fears that the problem is on course to get worse without action, due to an ageing staff demographic and too few replacements.

The report also detailed evidence that the low number of specialist nurses for sickle cell care means that patients encounter healthcare professionals without the appropriate knowledge of their condition, which exacerbates issues around stigmatisation, lack of joined-up care and care failings.

Since taking over as Chair of the APPG on Sickle Cell and Thalassaemia in July 2022, I have repeatedly

raised these findings and pressed for action in Parliament, including on the important issue of nursing in the sickle cell workforce. This new report is a welcome development in setting out the workforce challenges in sickle cell services and the steps required to address the problem.

The APPG on Sickle Cell and Thalassaemia will continue to advocate for more action from health ministers and healthcare leaders to improve sickle cell care, including on the recommendations contained in this report. I look forward to continuing to work with the inspirational sickle cell community as we take this forward.

Janet Daby MP – Chair, All-Party Parliamentary Group on Sickle Cell and Thalassaemia



As the country's first specialist sickle cell nurse, I am proud of the contribution specialist nurses have made – and continue to make – to sickle cell patients' care. However, thanks to this experience I am also sadly all too familiar with the history of under-prioritisation of sickle cell patients and understaffing of the services they rely on, which means the level of specialist nursing support for sickle cell patients has never met the level required.

Dedicated, expert specialist sickle cell nurses play an absolutely crucial role in delivering care to sickle cell patients. Many patients say that it is only sickle cell specialists (both nurses and consultants) who fully understand their condition and provide them with the care they need.

Understanding the scale of the problem is an essential precursor to addressing it. The Sickle Cell Society's efforts to secure data on the specialist sickle cell nursing workforce for this report was concerning in this regard. For example, at the start of this project, NHS England advised that it does not hold information on the number of specialist sickle cell nurses employed across the country, and a number of the regional lead hospital trusts for sickle cell also did not have records of how many specialist nurses are employed across the region they are responsible for.

However, through the evidence the Sickle Cell Society has gathered for this report, it is clear that there remains an insufficient number of specialist sickle cell nurses to meet the level required to deliver a routinely good standard of care to patients.

Earlier this year, NHS England published its Long Term Workforce Plan, which identified three clear priority areas: training new workers, retaining the existing workforce and making reforms to improve productivity. As this report outlines, action is urgently needed in all three areas to ensure sickle cell patients have access to the specialist nursing care they require.

While there are undoubtedly workforce challenges across all parts of the health system, the evidence in this report suggests that sickle cell is disproportionately impacted as a result of the legacy of under-prioritisation of sickle cell care. There is therefore a particularly strong case for the prioritisation of sickle cell services as part of the implementation of the NHS Long Term Workforce Plan.

I call on all those identified in this report's recommendations to play their part in ensuring the sickle cell workforce reaches the level required to deliver a consistently good standard of care to patients.

**Dame Elizabeth Anionwu –
Patron, Sickle Cell Society**

EXECUTIVE SUMMARY

Sickle cell services have faced decades of underfunding and under-prioritisation, as outlined in the *No One's Listening* report published by the Sickle Cell Society and the All-Party Parliamentary Group on Sickle Cell and Thalassaemia in 2021. This is reflected in the challenges facing the specialist sickle cell nursing workforce.

This research project set out to capture the wide-ranging role specialist sickle cell nurses perform, gain a more detailed understanding of the current level of specialist sickle cell nurse staffing, the impact this has on patients and clinicians, the reasons behind

the workforce shortage, and what needs to happen to ensure there are sufficient numbers of specialist nurses to deliver a good standard of care to people with sickle cell disorder. This report sets out our findings.



What do specialist sickle cell nurses do and how does it benefit patients?

Specialist sickle cell nurses undertake a wide range of vital roles to support patients. This includes running and assisting with clinics, supporting patients presenting at Emergency Departments in sickle crisis, educating and advising colleagues who are not specialists in sickle cell, and providing advice and guidance on managing the condition for patients and their loved ones, including couples during and after pregnancy.

As well as the clinical support most would associate with the role, specialist sickle cell nurses often provide more wide-ranging social support to their patients, often outside of their official duties, from offering advice and support with securing welfare payments to guiding patients as they navigate life developments such as going off to university. This wide-ranging support is hugely beneficial to sickle cell patients, with specialist nurses (and consultants) regularly cited by patients as providing the best care they receive.

Is the specialist sickle cell nursing workforce level sufficient?

The overwhelming consensus among sickle cell healthcare professionals, patients, patient carers/relatives and relevant organisations is that there is an insufficient number of specialist sickle cell nurses to deliver a good standard of care to patients.

This is supported by the data, which shows that there is a lower number of specialist sickle cell nurses in many areas of the country than recommended by experts as the level required to enable routine delivery of a good standard of care.

There is a high degree of regional variation in the sickle cell nursing workforce level across the country, and particularly in the commissioning and availability of community-based sickle cell nursing support.

Evidence from patients and healthcare professionals suggests that the sickle cell workforce is disproportionately low (even in a context of workforce challenges across the health system). This is supported by data comparisons which show that, accounting for the respective number of patients, the specialist nursing workforce for sickle cell is lower than for cystic fibrosis, a similar condition.

The majority of the experts who contributed to our research felt that the future prospects for the specialist sickle cell nursing workforce look bleak without a change in approach, with particular concern about forthcoming retirements among an ageing workforce without succession plans in place.

Impact of specialist sickle cell nursing workforce shortages

Over the course of our inquiry, we heard that the shortage of specialist sickle cell nurses has a profound impact on patients and their carers, but also on specialist nurses and their clinical colleagues.

The shortage of specialist sickle cell nurses means that patients' care is frequently impacted by encountering nurses who do not have sufficient knowledge of sickle cell to deliver a good standard of care. Specialist sickle cell nurses often do not have the time to engage with patients in the way that they would like, impacting their ability to properly explore problems patients are experiencing. This leads to some patients taking extreme measures, such as

delaying or avoiding attending hospital due to their expectation of inadequate care.

Specialist nurses and other clinicians are frequently stressed, tired and overworked, leading to low morale and burnout. Nurses who want to provide the highest possible level of care to their patients feel distressed when they are unable to do so due to capacity constraints. The situation is such that some specialist sickle cell nurses are choosing to leave the profession altogether.

Why are there too few specialist sickle cell nurses?

There are a range of factors that mean there are too few specialist sickle cell nurses. There is a lack of funding for specialist sickle cell nursing posts but also too few nurses wanting to specialise in sickle cell. The two problems reinforce each other and ensure that the situation continues.

Funding for specialist sickle cell nursing posts is seen as harder to secure than for other types of nursing positions, often connected to under-prioritisation of sickle cell among healthcare leaders and management.

There is a perception among many nurses choosing a specialism that sickle cell care is an undesirable area to choose to work in. This can be due to nurses justifiably deciding that they do not wish to work in a particularly under-resourced area of healthcare. However, we were also told that sometimes prejudicial attitudes affect perceptions around the desirability of working with sickle cell patients.

Insufficient training in sickle cell and a lack of exposure to sickle cell patients in the early years of nurses' careers also impact the number of nurses who choose to specialise in sickle cell. Nurse training curriculums still do not contain sufficient (or sometimes any) training on sickle cell, and there is a lack of opportunity for further training in sickle cell for nurses once they have qualified.

A lack of opportunity for career progression can also serve to deter nurses from specialising in sickle cell. We heard that the limited number of posts available in sickle cell care compared to other areas mean that there are fewer options for career progression and development, with few senior-level positions available and sickle cell roles falling under a lower band than for equivalent roles in other conditions. The huge range of job titles and role duties can also be confusing to those interested in specialising in sickle cell nursing.

What needs to happen to address the specialist sickle cell nursing workforce shortage?

Based on the evidence we received, the Sickle Cell Society makes the following recommendations:

Defining and mandating a minimum specialist nurse/patient ratio

- NHS England to develop a national standard for a minimum specialist nurse/patient ratio that must be met by each Haemoglobinopathies Coordinating Centre region.
- NHS England's national standard outlining the specialist nurse/patient ratio should be for a minimum of one specialist sickle cell nurse per 100 registered sickle cell patients registered with the service.
- NHS England to direct that the nurse/patient ratio should be commissioned and implemented on a proportional basis i.e. under a one-specialist-nurse-per-100-registered-patients ratio, a service with 25 patients would be required to employ a specialist nurse to cover sickle cell on a 0.25 working time equivalent (WTE) basis.

Increasing and making best use of funding for sickle cell services

- NHS England to undertake a review of current national sickle cell workforce provision to assess where need is greatest, and allocate NHS Long Term Workforce Plan-linked funding for new nursing places accordingly for sickle cell services.
- Integrated Care Systems to take a flexible approach to funding new specialist sickle cell nursing roles, ensuring opportunities for recruitment are acted upon when they arise.
- NHS England to review how sickle cell nursing roles are currently commissioned across the country, in order to establish a more cohesive approach to sickle cell service commissioning that ensures greater alignment between acute and community-based care.

There is a lack of funding for specialist sickle cell nursing posts but also too few nurses wanting to specialise in sickle cell.

Increasing sickle cell training and experience

- Universities, colleges, the Nursing and Midwifery Council and Royal College of Nursing to work with the Sickle Cell Society to ensure that sickle cell features adequately in the curriculum for nurse training courses.
- Nursing and Midwifery Council to develop a standardised national training model for nurses training to specialise in sickle cell, which includes gaining practical experience of the full range of sickle cell care.
- Haemoglobinopathies Coordinating Centres and Integrated Care Systems to offer shadowing, secondment and link nurse opportunities to those who have expressed an interest in sickle cell care, in line with the NHS Long Term Workforce Plan's emphasis on a flexible approach to career pathways.

Ensuring greater opportunity for progression

- NHS England to undertake a review of current banding, responsibilities and job titles for specialist sickle cell nurses, to be followed by publication of clear parameters on the competencies and duties required for each band level, building on the forthcoming Royal College of Nursing publication, *Caring for people with sickle cell disease and thalassaemia syndromes – A competency framework for nursing staff 2nd Edition*.
- Integrated Care Systems to provide funding for specialist sickle cell nurses to undertake further training in areas such as delivery of apheresis procedures and leadership and management.

Increasing collaboration and forums for mutual support

- STANMAP to consider diversifying location of meetings and ensure meetings are advertised with sufficient notice.
- STANMAP and/or new regional networks to consider establishing new forums for collaboration and support for specialist sickle cell nurses, such as WhatsApp/Facebook groups.
- All Haemoglobinopathies Coordinating Centres to establish regular clinical supervision support groups for their specialist sickle cell nurses.

Adopting measures to increase specialist sickle cell nurses' capacity

- National Haemoglobinopathy Panel to undertake a review to identify opportunities to make use of other NHS resources to reduce workloads of specialist sickle cell nurses, such as paediatric transition nurses, Advanced Nurse Practitioners and physicians' associates.
- Integrated Care Systems to facilitate greater integration with third sector services and other statutory services to reduce non-clinical workload of specialist sickle cell nurses.
- Integrated Care Systems to use new funding for innovative medical technology announced in October 2023 to improve sickle cell services, such as through greater automation of administrative functions and the use of remote digital patient monitoring.

INTRODUCTION

Sickle cell, a hereditary condition, is a disorder of the haemoglobin in red blood cells. Haemoglobin is the substance in red blood cells that is responsible for the colour of the cell and for carrying oxygen around the body.

The main symptoms of sickle cell disorder are anaemia and episodes of severe pain. The pain occurs when the cells change shape after oxygen has been released. The red blood cells then stick together, causing blockages in the small blood vessels. These painful episodes are referred to as a sickle cell crisis.

It is estimated that a minimum of 17,500 people are living with sickle cell disorder in England, with the vast majority of African-Caribbean heritage.

Sickle cell services have faced decades of underfunding and under-prioritisation. The Sickle Cell Society's 2021 report, *No One's Listening*, published in partnership with the All-Party Parliamentary Group on Sickle Cell and Thalassaemia, explored the care failings sickle cell patients face. The report detailed a range of issues, including: sub-standard care on general wards and in Emergency Departments; failings in providing joined-up sickle cell care; low awareness of sickle cell among healthcare professionals and inadequate training; negative attitudes towards sickle cell patients; and inadequate investment in sickle cell care.

In the two years since the report was published, there has been some progress:

- NHS England initiated a review of sickle cell care pathways which identified ten Quality Improvement Actions to be addressed for sickle cell services.
- The NHS Race and Health Observatory commissioned workstreams related to sickle cell care, with one of these resulting in a report published in January 2023 on digital interventions for sickle cell care.
- Following these pieces of work, the roll-out of universal digital care plans for sickle cell patients is currently being taken forward.
- In June 2022, NHS England launched a campaign to increase awareness of the key signs and symptoms of sickle cell disorder among emergency care staff, carers and the wider public.
- On World Sickle Day in June 2023, NHS England announced the creation of new 24/7 Hyper Acute Units in parts of the country with the highest number of sickle cell patients to allow people to bypass Emergency Departments during a sickle crisis.

Nevertheless, there remains much to be done to address the legacy of past underfunding and under-prioritisation, with addressing the shortfall in the specialist sickle cell nursing workforce key among them, as this report will outline.



METHODOLOGY

This report's evidence was gathered via the following methods:

- Publication of a call for written evidence, which led to the receipt of 28 submissions from organisations and individuals, including nurses, other healthcare professionals and organisations, patients and patient carers/relatives.
- Nine interviews with relevant experts, including specialist sickle cell nurses, consultant haematologists and patient relatives.
- A focus group with specialist sickle cell nurses at a meeting of the Sickle Cell & Thalassaemia Association of Nurses, Midwives and Allied Professionals (STANMAP).

- Freedom of Information requests to Haemoglobinopathies Coordinating Centres (HCCs) and NHS Trusts, as well as direct contact with HCC Network Managers, to gain quantitative data.
- Analysis of existing data, via the National Haemoglobinopathy Register.

There are a range of job titles used for specialist nurses delivering sickle cell care. Many also cover thalassaemia and other rare red cell anaemias. For the purposes of this report, we have generally adopted the catch-all term 'specialist sickle cell nurse'.

WHAT DO SPECIALIST SICKLE CELL NURSES DO AND HOW DOES IT BENEFIT PATIENTS?

The specialist sickle cell nurse role is one that has evolved over the last four decades, starting with Dame Elizabeth Anionwu as the UK's first in 1979. The role was initially primarily focused on antenatal and newborn care but, as treatment developments led to life expectancy for sickle cell patients extending well into adulthood, the role developed to provide the lifelong care sickle cell patients require.¹

Clinical care and support

“Specialist nurses are the foundation of the service that we provide.”

– Dr Subarna Chakravorty, Consultant Paediatric Haematologist, King's College Hospital NHS Foundation Trust

Specialist sickle cell nurses undertake a wide range of vital roles to support patients. The clinical care provided by specialist sickle cell nurses includes running clinics and supporting consultant-led clinics. They play a key role in assessing patients and often provide treatments including red cell exchange, hydroxycarbamide and crizanlizumab. Consultant Haematologist Dr Joe Sharif explained that the nurse-led hydroxycarbamide clinic in his NHS Trust in Manchester has been a huge help in ensuring he has capacity to see patients with other issues in his own clinic.² Similarly, Consultant Paediatric Haematologist Dr Subarna Chakravorty, told us that nurse-led clinics take an “enormous load” off

consultants' clinical duties and are often able to be more flexible to patients' availability than consultant-led clinics.³

When patients present at Emergency Departments with a sickle crisis, having a specialist sickle cell nurse attend can help to improve the care they receive. Having a known and trusted presence can provide huge reassurance to patients and their loved ones. The presence of a specialist sickle cell nurse can also be a crucial source of support for their colleagues in the Emergency Department, who, as specialist sickle cell nurse Andy Houghton explained, might be having “their first experience ... of sickle cell disease”.⁴ The presence of a specialist sickle cell nurse can help to ensure that pain relief standards are adhered to and that observations are carried out regularly.

The role specialist sickle cell nurses play in educating and supporting colleagues who are not specialists in sickle cell was also emphasised by Consultant Haematologist Dr Josh Wright, who described them as “really important to the ongoing education within

1 Keisha Osmond-Joseph, written evidence

2 Dr Joe Sharif, interview, Wednesday 10 May 2023

3 Dr Subarna Chakravorty, interview, Friday 21 April 2023

4 Andy Houghton, interview, Wednesday 26 April 2023

your own department” by “building competencies amongst the wider nursing staff for inpatient care”.⁵ Specialist sickle cell nurse Kim Newell described part of her role as ensuring operational protocols and procedures are up to standard so that clinical colleagues are able to access it and provide a good standard of care to sickle cell patients.⁶

Another specialist sickle cell nurse, Sandy Hayes, described part of her role as being “enabling and facilitating the ward staff so that they can do what they need to do for these patients and have a good understanding of the care that’s required”, making the point that “there’s no point in having a specialist nurse who comes in and does everything because if she goes off with Covid or breaks her leg or is on leave, nobody knows what to do.”⁷

“The specialist nurses are often the frontline of the communication between patients and medical services.”

– Dr Josh Wright, Consultant Haematologist, Sheffield Teaching Hospitals NHS Foundation Trust

Specialist sickle cell nurses are a key source of advice and guidance on managing the condition for patients and their loved ones. Often, it is specialist nurses that are the first point of contact, which allows them to build relationships with patients. Dr Josh Wright noted that the nature of sickle cell as a health condition means that “you might be looking after patients for years, even decades ... so those relationships that you build up over time are absolutely crucial to the trust and quality of care that is delivered, and a lot of that actually falls on the specialist nurses. They are the ones who often develop the longer-term relationships with patients and are the contact points. Very often, I get information fed back to me from our specialist

nurses about patients and what problems they may be experiencing outside the hospital or the fact that they sound like they’re going to be coming in very shortly.”⁸

Sandy Hayes argued that this educational role is vital, noting that specialist sickle cell nurses provide a lot of health promotion information for patients, “ensuring that they understand why it is that we’re doing the things that we do. They absolutely have to understand what it is that you’re asking them to do and why ... So actually, their decision-making comes from a base of knowledge rather than just, ‘well, the doctors have told me to do this’.”⁹

Dr Subarna Chakravorty also highlighted that specialist sickle cell nurses provide a “huge amount” of clinical advice and that, “if this advice was not there, then the families would often be coming to the Emergency Department”.¹⁰ Likewise, Consultant Haematologist Dr Martin Besser noted the importance of telephone advice by nurses, citing a recent example where a patient had told him, “I thought about getting myself admitted, but then I rang the nurses”.¹¹ This provision of advice has the dual benefit of reducing patient suffering and preventing unnecessary hospital visits, which Dr Chakravorty argued should be acknowledged by NHS leaders as an economic benefit of specialist sickle cell nurses’ work.¹²

The advice provided by specialist sickle cell nurses is also crucial in supporting couples during and following pregnancy. Iyamide Thomas, whose role with the Sickle Cell Society focuses on sickle cell screening programmes, highlighted research in 2017 that found couples at risk of having a child with sickle cell reported that only specialist haemoglobinopathy nurses and midwives understood the issues of an at-risk pregnancy and the need to expedite the screening process.¹³

5 Dr Josh Wright, interview, Tuesday 23 May 2023

6 Kim Newell, interview, Tuesday 20 June 2023

7 Sandy Hayes, interview, Thursday 27 April 2023

8 Dr Josh Wright, interview, Tuesday 23 May 2023

9 Sandy Hayes, interview, Thursday 27 April 2023

10 Dr Subarna Chakravorty, interview, Friday 21 April 2023

11 Dr Martin Besser, interview, Monday 26 June 2023

12 Dr Subarna Chakravorty, interview, Friday 21 April 2023

13 Iyamide Thomas, written evidence, citing Public Health England, *Parents’ Stories* (2017): <http://www.sicklecellsociety.org/wp-content/uploads/2018/05/Parents-stories-publication-July-2017.pdf>. Accessed 3 November 2023

Specialist sickle cell nurses often play a key role during the transition from paediatric care to adult services. Andy Houghton described to us the coordination they undertake with Alder Hey Children’s Hospital, with “several transition clinics each year ... We like to start meeting them about

the age of 15, and then we’ll catch them once when they’re 16, and when they’re 17 we’ll go to a couple of their clinics as well, just to start the transition. So they’ve met us a few times before they come over.”¹⁴ This helps to ensure continuity of care and a more positive patient experience.

Social support

As well as the clinical support most would associate with the role, specialist sickle cell nurses often provide more wide-ranging support to their patients, often outside of their official duties, from offering advice and support with securing welfare payments to guiding patients as they navigate life developments such as going off to university. As Dr Josh Wright told us, specialist sickle cell nurses are “also psychologists and social workers sometimes thrown into the mix”.¹⁵

We heard a number of examples of this wider support for patients. Describing his role as a specialist nurse, Andy Houghton said that in addition to being there to provide clinical advice, “we’re also here for social advice, for economic advice ... we can help with things like housing and benefits and things like that”.¹⁶ Sandy Hayes also referred to helping people with Personal Independence Payment applications and attending and advocating for patients during meetings with their employers to ensure they have suitable working conditions.¹⁷

She also told us, “if there’s a patient who’s really complex and is in hospital in another hospital [within their sickle cell care network] I get in my car and I go down and see them, help the local team, especially if there’s some major psychosocial or psychological issues going on. I’ll go in and do a really in-depth assessment and then get people involved. So by doing that I have discovered domestic abuse, I’ve discovered all sorts of things.”¹⁸

Sandy Hayes also referred to supporting international students studying at university in Oxford and encountering cold weather – and its impacts on their sickle cell disorder – for the first time. As well as providing education around the condition, “I’ve even taken the young people to the charity shops to show them where they can buy cheap warm clothing and the layers that you can use”.¹⁹

Lynette, who has two children of young adult age with sickle cell, provided an example of the counselling support specialist sickle cell nurses often provide. When her daughter wanted to go on a trekking trip in Namibia, it was their specialist sickle cell nurse who was able to persuade her that the prospect of being at high altitude, miles from the nearest town, was too dangerous. Lynette told us that “that counselling role has been wonderful ... that whole thing of trust and the relationships that those liaison nurses have to build is crucial”.²⁰

These examples demonstrate the wide-ranging support sickle cell nurses provide to patients that may be difficult to quantify but are evidently hugely beneficial.

14 Andy Houghton, interview, Wednesday 26 April 2023

15 Dr Josh Wright, interview, Tuesday 23 May 2023

16 Andy Houghton, interview, Wednesday 26 April 2023

17 Sandy Hayes, interview, Thursday 27 April 2023

18 Ibid.

19 Ibid.

20 Lynette, interview, Tuesday 13 June 2023 [full name withheld by request]

Benefit to patients

While many sickle cell patients and their carers have a negative view of the non-specialist nursing care they receive – as outlined in the *No One's Listening* report – many of those we heard from praised the care they received from specialist nurses.

Referring to the community specialist sickle cell nurse who has supported her family for many years, Lynette said: “We just owe so much to her in terms of guiding us in those early days when we knew pretty much nothing about sickle cell ... she has been by our side through all the years of being in and out of hospital and so on.”²¹

Carol Burt, parent to a young person with sickle cell, said that specialist sickle cell nurses play a vital role in ensuring patients feel they have someone advocating on their behalf, supervising their care and accompanying them through the care pathway.²²

Elizabeth Blankson-Hemans noted that specialist sickle cell clinics are “the one place I can marginally relax and know that nurses have a good enough knowledge to be able to provide a decent level of nursing care”.²³ Laurel Brumant-Palmer said that specialist sickle cell nurses “are amazing and go over and beyond in the levels of care that they give to us as sickle cell patients ... every encounter I have had in my lifetime with them has been the most special experience as a patient living with a chronic illness requiring regular admission to hospital”.²⁴ However, both caveated this praise with the assertion that there are not enough specialist sickle cell nurses.

²¹ Ibid.

²² Carol Burt, written evidence

²³ Elizabeth Blankson-Hemans, written evidence

²⁴ Laurel Brumant-Palmer, written evidence



IS THE SPECIALIST SICKLE CELL NURSING WORKFORCE LEVEL SUFFICIENT?

The overwhelming consensus among patients, patient carers, healthcare professionals and medical organisations we heard from during our inquiry was that the current level of specialist sickle cell nursing workforce is insufficient to routinely provide a good standard of care for sickle cell patients. Quantitative data secured for this project also supports this conclusion.

The current situation

Data secured for this project revealed that there is a lower number of nurses employed per patient in many areas of the country than recommended by the experts we spoke to. While opinions varied, we most commonly heard that ensuring routine delivery of a good standard of care requires, at minimum, one specialist nurse employed for every 100 patients registered with a sickle cell service. However, based on the data we were able to secure, only two of the ten regional areas by which sickle cell care is divided in England currently meet this threshold, with six having a worse specialist nurse/patient ratio (and two where we were unable to secure data at all or unable to secure region-wide data).²⁵

This quantitative evidence was supported by the qualitative evidence we received. All of the patients who provided testimony to the inquiry told us their experience was of an insufficient number of specialist sickle cell nurses. Lowlah Bloom told us: “I haven’t had one admission in over a decade [where] I haven’t heard, ‘We’re under staffed’ or ‘we have other patients to deal with’ ... We had the same issue in the 80s, not enough sickle cell nurses. And nothing has changed in 2023.”²⁶

Richard Patching, whose wife Carol has sickle cell disorder, said that, while the specialist sickle cell nurses he encounters “are excellent ... there are clearly not enough sickle cell nurses regionally”, with no specialist sickle cell nurses employed at their local hospital.²⁷

“The amount of work that you have to do is just too much to get the best output to the patients.”

– Anonymous specialist sickle cell nurse
[name withheld by request]

Stephanie George told us that, in her area, there is one specialist sickle cell nurse based in the acute setting and one in the community and that this is not sufficient: “There are so many patients that attend the hospital and access services in the community, having one of each is not enough. Their workload is extremely heavy and resources are limited. We need more specialist nurses.”²⁸

²⁵ Data obtained by the Sickle Cell Society via Freedom of Information requests and directly from Haemoglobinopathies Coordinating Centres

²⁶ Lowlah Bloom, written evidence

²⁷ Richard Patching, written evidence

²⁸ Stephanie George, written evidence



Healthcare professionals echoed these views on the current specialist sickle cell nursing workforce level. Consultant Haematologists noted the shortfall, with Dr Thomas Lofaro telling us that his service has very dedicated staff but that “staffing is at best termed ‘skeletal’.”²⁹ Dr Josh Wright said “I doubt there is a really well-staffed sickle team anywhere in the country” and Dr Subarna Chakravorty said “we have always felt there is a big gap of specialist nurses all across the country, everywhere [and for] all age groups”.^{30 31}

Specialist sickle cell nurses themselves also expressed their concerns. Bernadette Hylton stated that there is a “significant shortage of nurses working

in roles that specialise in sickle cell disease, in all settings i.e. community and nurse specialists”.³² Keisha Osmond-Joseph noted that a 2017 NHS England report predicted that 23% of sickle cell and thalassaemia specialist nurses were due to retire within the next five years (as well as 27% of consultants) and that, “six years on from that document, this has come to fruition, as many services have lost and continue to lose experienced and accomplished senior leaders, with very little or no succession planning ... Recruitment into CNS [clinical nurse specialist] roles can be challenging, with few applicants and most requiring significant input to upskill to what services now require.”³³

29 Dr Thomas Lofaro, written evidence

30 Dr Josh Wright, interview, Tuesday 23 May 2023

31 Dr Subarna Chakravorty, interview, Friday 21 April 2023

32 Bernadette Hylton, written submission

33 Keisha Osmond-Joseph, written evidence

Kim Newell also highlighted recruitment challenges and the lack of new specialist nurses, telling us that when new specialist nurse appointments are made it is often “just circulating a lot of the same nurses, so you’re not getting a new nurse, you’re getting a nurse from another sickle cell centre or you’re getting a nurse from another day unit”.³⁴ Likewise, Dr Kofi Anie MBE, Consultant Psychologist at London North West University Healthcare NHS Trust, said that often with specialist sickle cell nursing recruitment, “it’s the same group of nurses that are moving around from Trust to Trust”.³⁵

“There are definitely not enough nurses to provide safe sickle cell disease care. This is concerning because it is a condition that can deteriorate so quickly within the acute setting, and a lack of nursing staff can significantly exacerbate morbidity and mortality rates among this patient cohort.”

– “SY”, specialist sickle cell nurse [full name withheld by request]

Haematology Nurse Madeleine Glover also argued that “the pipeline ... is not as strong” for specialist sickle cell nurses as for other branches of nursing as “there is a shortage of nurses who want to pursue a career of uphill battles, under-representation and institutional racism as barriers to providing good care”.³⁶ Without increasing the pool of specialist sickle cell nurses, new appointments can simply be rearranging the distribution of the workforce rather than addressing the overall workforce challenge.

Medical bodies supported these individual perspectives. The British Society for Haematology told us that there is “a dearth in number of nurses in England to care for sickle cell patients, both in acute and community settings”.³⁷ The NHS Race and Health Observatory echoed this: “We clearly know there are not enough nurses who have received specialist training to provide a good level of care for sickle cell patients amidst the current levels of general vacancies for nurses.”³⁸ The North Central London and East of England Haemoglobinopathies Coordinating Centre (HCC) stated that “there are not a sufficient number of specialist nurses in all areas (community, acute CNS, day unit/apheresis or inpatient settings)”.³⁹

34 Kim Newell, interview, Tuesday 20 June 2023

35 Dr Kofi Anie MBE, interview, Friday 16 June 2023

36 Madeleine Glover, written evidence

37 British Society for Haematology, written evidence

38 NHS Race and Health Observatory, written evidence

39 North Central London and East of England Haemoglobinopathies Coordinating Centre, written evidence

Community nursing and nurse counselling

Although the specialist sickle cell nursing workforce level is generally felt to be inadequate across all settings, we heard that the situation is particularly bad in relation to community nursing support and nurse counselling. Both are necessary forms of support for sickle cell patients.

This was attested to by Consultant Haematologists we spoke to. Dr Josh Wright explained that the role of a community nurse is “vital in terms of understanding what’s going on outside hospital” and in providing genetic counselling.⁴⁰ Dr Joe Sharif said that “their role is really valuable. They help support patients at home, address social issues, assist with educational or occupational barriers; they also help to plug patients back into the system when they have been lost to follow-up”.⁴¹

In spite of its importance, this community nursing support is often lacking or entirely absent. The British Society for Haematology said that “there is virtually no community nurse specialist support in most regions in England” for sickle cell.⁴² Dr Martin Besser said that to find the nearest community nurse to his patients in Cambridge, “you’d have to go to north London; it’s about 45 miles from here”.⁴³

Dr Subarna Chakravorty said that community nurses in her area are largely restricted to providing antenatal care due to understaffing: “There is no time for anything else. So although they are meant to be community-based nurses providing out-of-hospital care to patients, either in terms of post-discharge care, or in terms of avoiding hospital admissions, improving quality of life, things that you would expect community nurses to be able to do, providing vaccinations in the community, helping with medications, the basic things that a nurse would be able to do, none of that is done. All of the time is spent either covering each other’s leave, because they’re always understaffed, or essentially just talking

to pregnant women and asking them to be referred to antenatal screening.”⁴⁴

Patients and their carers described the inadequate level of community nursing in their areas. Stephanie George said there is just one community specialist sickle cell nurse in her area who is “fantastic ... but there’s only so much she can do, there needs to be a team of nurses”.⁴⁵ Araba Mensah told us: “There is absolutely no care in the community and, once out of hospital, patients are left without any support to cope on their own. Sickle cell imposes such a heavy burden on patients and families that we need a strong support system.”⁴⁶

Based on the testimony provided by specialist sickle cell nurses we spoke to, the situation with respect to community support may even have worsened recently, at least in some areas. Leanne Mawer said: “I used to share my workload in hospital and the community visiting families. Covid stopped me doing the community side of my work. I’m now not allowed to restart this due to staffing levels.”⁴⁷ Likewise, Doreen Richards told us she used to work in the community but that this aspect of the service had been withdrawn despite there still being “a demand of patients requesting information and care in the community”.⁴⁸

Some felt that the level of patient need for community nursing is underestimated. Fiona French said that sometimes when patients move to a new area, they refuse transfer of care to their new local centre for a variety of reasons, meaning the number of patients seen in hospital is not reflective of the numbers in the community.⁴⁹ Similarly, another specialist sickle cell nurse noted that when young adults go off to university somewhere else in the country, they often keep their scheduled acute care at their home address, meaning their need for

40 Dr Josh Wright, interview, Tuesday 23 May 2023

41 Dr Joe Sharif, interview, Wednesday 10 May 2023

42 British Society for Haematology, written evidence

43 Dr Martin Besser, interview, Monday 26 June 2023

44 Dr Subarna Chakravorty, interview, Friday 21 April 2023

45 Stephanie George, written evidence

46 Araba Mensah, written evidence

47 Leanne Mawer, focus group at STANMAP meeting, Thursday 29 June 2023

48 Doreen Richards, focus group at STANMAP meeting, Thursday 29 June 2023

49 Fiona French, focus group at STANMAP meeting, Thursday 29 June 2023



community care in the area they have moved to is not recognised.⁵⁰

Nurse counselling was felt to be similarly important, yet not sufficiently available. Consultant Psychologist Dr Kofi Anie noted that living with a chronic condition like sickle cell is “emotionally very challenging psychologically [and] difficult to cope with on a day-to-day basis”, which requires therapeutic support. Yet, “everybody knows that there’s insufficient support. If you talk to patients, they’ll tell you that they don’t get enough psychological support across the board.”⁵¹

The North Central London and East of England HCC said that there are “inadequate numbers [of nurse counsellors] to provide a safe, easily accessible service and often staff doing multiple roles and double counted”.⁵² The NHS Race and Health Observatory told us that none of the patients that took part in focus groups for its sickle cell digital discovery project were part of a nurse counselling programme.⁵³

50 Anonymous, focus group at STANMAP meeting, Thursday 29 June 2023

51 Dr Kofi Anie MBE, interview, Friday 16 June 2023

52 North Central London and East of England Haemoglobinopathies Coordinating Centre, written evidence

53 NHS Race and Health Observatory, written evidence

Regional variation

Within the context of across-the-board workforce shortages for sickle cell, there is also considerable regional variation. As outlined above, the data secured for this report showed that only two of the ten regional sickle cell care networks had a specialist nurse/patient ratio that was above the minimum threshold experts told us needed to be met to provide a routinely good standard of care, with the best staffed of these having one full-time equivalent specialist nurse for every 87.68 patients. By contract, six of the regional sickle cell care networks we were able to secure data for had a sub-optimal specialist sickle cell nurse/patient ratio, with the most poorly-staffed having one full-time equivalent specialist nurse for every 199.7 patients.⁵⁴

Even within these regional networks, there is considerable variation. There are multiple NHS Trusts in each regional network and every NHS Trust is designated as either a Specialist Haemoglobinopathies Team (SHT) or a Local Haemoglobinopathies Team (LHT). As might be expected, SHTs are generally better staffed and see more patients. However, many NHS Trusts designated as an LHT either have no specialist sickle cell nurses at all or – where they do have any level of specialist sickle cell nurse capacity – it is even more stretched than is the case generally across the country.

A specialist sickle cell nurse based in a town near London noted that the area is classed as an LHT which means people “assume you have simpler cases” but that “as people move out of central London, I find our numbers just going up and up and up [and] over time I’m finding a lot of the local centres are getting a lot more complicated cases”. They told us that the current designation of SHT or LHT only takes into account patient numbers but “they don’t look at how complicated the actual cases that you’re managing are ... Certainly, the haematologist that comes out to support us from a specialist centre ... keeps saying, ‘you’ve got such complicated cases here and your numbers are rising’”.⁵⁵

Sandy Hayes referred to a nurse working at an LHT within her regional network whose role is supposed to include two days a week focusing on sickle cell care but “she isn’t able to because she keeps getting dragged into other stuff and that’s a real shame ... their time [focusing on sickle cell care] needs to be protected”.⁵⁶

Another example of variation within a regional network was provided by a specialist sickle cell nurse whose role covers a wide area from north-west London out into Bedfordshire. They told us this makes it “quite difficult when you’re based in London to know about the services around that area and to support families locally, as well as our growing caseload in London ... now with more movement around London and out of London, that probably is something that is having an impact on the level of care. I’m only one person, so it’s very difficult to provide that level of care that was there before.”⁵⁷

Dr Martin Besser, a Consultant Haematologist based in Cambridge, outlined the effects of the variation in capacity and expertise within his regional network, telling us that their status as an SHT means “we’re pulling from the region ... There are 900 patients in the region; we’re looking after 100. There are quite a few people who are accepting less than optimal care from their existing hospital” so they come to Cambridge as an SHT. Although they are happy to be able to provide this better care to patients, “we’re struggling a bit, keeping up with all the slots”.⁵⁸

Terumo BCT – a medical devices company that manufactures transfusion therapies devices used for sickle cell care – described regional variation in access to blood transfusion for sickle cell patients: “Sickle cell patients located at smaller cities and particularly in the midlands experience geographical disparities in their access to treatment due to shortage of staff. This means that there is minimal access to automated red blood cell exchange (aRCX) in specialist/large hospitals (one apheresis nurse revealed that every weekend service slot was fully booked for aRCX till 2024) [in May 2023].

⁵⁴ Data obtained by the Sickle Cell Society via Freedom of Information requests and directly from Haemoglobinopathies Coordinating Centres

⁵⁵ Anonymous, focus group at STANMAP meeting, Thursday 29 June 2023

⁵⁶ Sandy Hayes, interview, Thursday 27 April 2023

⁵⁷ Anonymous, focus group at STANMAP meeting, Thursday 29 June 2023 [name withheld by request]

⁵⁸ Dr Martin Besser, interview, Monday 26 June 2026

Many patients have therefore resorted to travelling miles to another centre or resorting to worse treatment options.”⁵⁹

“We need to have some [specialist] nursing time in hospitals even if they’ve got ten patients. Those ten patients still deserve the same sort of care that my patients would get in Oxford.”

– Sandy Hayes, specialist sickle cell nurse

The provision of community nursing support is also significantly variable across the country, with some areas having relatively good provision but most either understaffed or having no community nursing support at all. Different areas have different commissioning arrangements – with some areas having NHS Trusts that commission hybrid acute/community nursing positions, some having NHS Trusts that commission acute and community nurses as distinct roles, and some having an NHS Trust that commissions acute nurses and a completely separate NHS Trust that commissions community nurses – which further complicates matters.

For example, Dr Joe Sharif, a Consultant Haematologist in Manchester, said that, due to commissioning arrangements, community nursing support in his area only covers the smaller Manchester region, whereas the clinical team covers a wider geographical area. He told us: “If you have a Manchester postcode, you are receiving the community services, whereas if you’re further north, you rely on local primary care services to take on this role. Some of those patients, we’d find it harder to keep in the service and to keep up to date with what’s going on with them because there’s no-one there to support them in the community.”⁶⁰

Likewise, Bernadette Hylton, describing the situation in her area, said that “the area that is covered by the current community service does not represent the wide geographical area that the patients come from. We generally do not have community provision to those outside Camden and Islington, and a very limited service for those [within that area].”⁶¹

Dr Josh Wright, having had funding pulled for the specialist community nurse previously employed in his area, described the difficulties in convincing external organisations such as other NHS Trusts or Integrated Care Boards of the crucial role played by a community team: “I can’t get an answer to the question, ‘What have you done with this money and where has this post gone?’ I just sort of get blocked. In future ICBs will be more crucial, though in many areas they are pretty rudimentary at this time. I believe that one of their key roles is to deal with local health inequalities and this might provide us with opportunity.”⁶²

Specialist nurses we spoke to had markedly different experiences of joining up care between acute services and the community depending on the commissioning arrangements in their area. Kim Newell told us that, in her area, “the interface of how the hospital and the community works probably could be streamlined a lot better.”⁶³ By contrast, Sandy Hayes, a specialist sickle cell nurse whose role is commissioned as covering both acute and community settings, said that this means “if a patient wants a home visit, then I’ll do a home visit. If I’m particularly concerned about how someone is managing and it looks like they should be having some equipment and things in their house but actually they don’t want to ask their GP then I ask if they would like me to come out and have a look for them, so that they’ve got a known person coming into their home rather than a stranger.”⁶⁴

As Dr Thomas Lofaro told us, “it is very concerning that very basic parts of care are allowed to be so unequal across the country. It appears that the only service offered to all is ‘emergency care’, and that care for sickle cell in particular is often overlooked.”⁶⁵

59 RPP Group UK, on behalf of Terumo BCT, written evidence

60 Dr Joe Sharif, interview, Wednesday 10 May 2023

61 Bernadette Hylton, written submission

62 Dr Josh Wright, interview, Tuesday 23 May 2023

63 Kim Newell, interview, Tuesday 20 June 2023

64 Sandy Hayes, interview, Thursday 27 April 2023

65 Dr Thomas Lofaro, written evidence



Disproportionate understaffing in sickle cell services

While it is undoubtedly the case that the NHS is facing severe workforce challenges across the board, many of those who fed into our project felt that sickle cell services are disproportionately affected.

Clinicians noted the contrast within haematology care for white blood cell conditions and red blood cell conditions such as sickle cell. Dr Martin Besser said that there is a perception that “white cell patients bring a whole lot more money and prestige for hospitals than red cell patients” and are therefore given more priority, meaning “it’s difficult to find trainees amongst the red cells because, historically, it’s a very frustrating area [to work in]”.⁶⁶ A haematology nurse likewise told us there is often more of a focus on malignant haematological

conditions and that sickle cell “is often clinically neglected in comparison to blood cancers”.⁶⁷

We also heard that the specialist sickle cell nursing workforce lags behind other similar chronic, inherited conditions, such as cystic fibrosis. Dr Martin Besser told it is “not on a par with other diseases” and Dr Kofi Anie said “cystic fibrosis seems to be more resourced than sickle cell”.^{68 69} The North Central London and East of England HCC told us that it is “much lower than these better funded areas.”⁷⁰ Terumo BCT said that, “in some hospitals the number of staff have only just reached parity [with specialist nurse staffing for conditions like cystic fibrosis and haemophilia], in others the level of nurse staffing for sickle cell is significantly inferior”.⁷¹

66 Dr Martin Besser, interview, Monday 26 June 2023

67 SY, written evidence [full name withheld by request]

68 Dr Martin Besser, written evidence

69 Dr Kofi Anie MBE, interview, Friday 16 June 2023

70 North Central London and East of England Haemoglobinopathies Coordinating Centre, written evidence

71 RPP Group UK, on behalf of Terumo BCT, written evidence

This is supported by available data. A report earlier this year on cystic fibrosis service resourcing reported that there are an average of 1.3 specialist nurses per 75 patients in adult cystic fibrosis services (and 1.8 per 75 patients in paediatric services).⁷² The data we secured for this project showed that the specialist nurse/patient ratio for sickle cell services is worse than this in every area of the country, with some regions seeing over double the number of patients per specialist nurse for sickle cell than the national average for cystic fibrosis.⁷³

One specialist sickle cell nurse told us that, in their experience, funding for recruitment is more readily available for other disease areas, citing an example in their hospital where interviews were taking place for a specialist nurse for another condition. Despite the interview being for only one post, both of the applicants interviewed were offered a position because they were considered good enough. While they told us there were likely good reasons for hiring both, “I haven’t seen that happen in the sickle cell world at all ... you’re just always fighting to get another nurse”, despite the service being “absolutely stretched”.⁷⁴ Dr Thomas Lofaro also highlighted that it is “often very hard to convince hospital leaders and

managers” of the importance of resourcing for sickle cell services.⁷⁵

As outlined in the Sickle Cell Society’s last report, *No One’s Listening*, there is an unavoidable link between under-resourcing and under-prioritisation of sickle cell services and systemic racial discrimination. One patient noted that, despite there being “thousands more sickle cell patients than cystic fibrosis and haemophilia, the levels of staff and money does not compare ... I feel as sickle cell affects [a] certain community and people of colour this determines type of care and outcomes. We are as a group disproportionately affected by health inequalities.”⁷⁶ Sickle cell patient Lowlah Bloom told us: “Illnesses that affect predominantly black people get less care and bother.”⁷⁷

Contributors to our inquiry were at pains to note that the last thing they would wish to see is resources taken away from other health areas and, indeed, that workforce challenges are an issue across the board. Nevertheless, there is a strong feeling that sickle cell is particularly badly affected and that addressing this disparity should be an urgent priority for healthcare leaders.

Expectations for the future

Several experts we heard from expressed some cautious optimism regarding the future of the specialist sickle cell nursing workforce. Dr Martin Besser predicted “gradual improvement” in the coming years.⁷⁸ Dr Subarna Chakravorty posited that “now that there is a little bit more interest in sickle cell because more exciting things are happening, newer drugs are coming through, newer technologies are coming through, maybe there might be more interest amongst newer nurses who want to further their careers.”⁷⁹

However, even gradual improvement is unlikely to be sufficient to address the scale of under-funding and under-prioritisation in sickle cell services up to now. Even these same experts who expressed cautious optimism also highlighted concerns and many more felt that the future prospects for the specialist sickle cell nursing workforce look bleak without a change in approach.

We heard from a haematology nurse that, unless something changes, “I imagine that the current situation we see with sickle cell disorder within the UK and Ireland will become worse and, as a nurse,

72 Cystic Fibrosis Trust, *UK Cystic Fibrosis Service Resourcing: 2020-2022* (2023): https://www.cysticfibrosis.org.uk/sites/default/files/2023-03/CF_Staffing_Report_UK_2023_FINAL.pdf. Accessed 3 November 2023

73 Data obtained by the Sickle Cell Society via Freedom of Information requests and directly from Haemoglobinopathies Coordinating Centres

74 Anonymous, interview [name withheld by request]

75 Dr Thomas Lofaro, written evidence

76 Claire T, written evidence [full name withheld by request]

77 Lowlah Bloom, written evidence

78 Dr Martin Besser, written evidence

79 Dr Subarna Chakravorty, interview, Friday 21 April 2023

I am worried about how this will manifest”.⁸⁰ Sickle cell patient Stephanie George told us “if healthcare professionals do not get the support they need, more will leave the profession and there will always be a shortage, meaning that patients like me will always have substandard care. We do not deserve that, and nurses do not deserve it either.”⁸¹

The British Society for Haematology said that, without a change in approach, they expect “significant shortfall in specialist nursing numbers, exhausted and stressed workforce, poor quality of patient care, leading to poor experience and outcome”.⁸² The NHS Race and Health Observatory said “we will see sickle cell disease grow across ethnic groups without a nursing workforce trained or equipped to help patients when they qualify.”⁸³

Terumo BCT singled out as an area of concern the apheresis-trained nursing workforce – crucial in the delivery of blood transfusions for sickle cell patients. They noted that many large pharmaceutical companies are looking to hire trained apheresis nurses due to a growing focus and interest in cellular therapies and told us: “A lead apheresis nurse revealed that four out of her eight nurses had left within the last year to work in a pharmaceutical company. If salary is not increased and more training and education is not focused on developing apheresis-trained sickle cell specialist nurses at all levels of healthcare, the nursing levels will fall.”⁸⁴

Many expressed concern about many specialist sickle cell nurses nearing retirement age without a clear plan in place for ensuring they will be replaced. Kim Newell warned that “a lot of the nurses that are circulating around at the moment are more to the latter end of their career. If they all retire then there’s going to be a really big problem and real gap in the knowledge base and in the nurses available to take up the job”.⁸⁵

Dr Josh Wright told us that “the specialist nurse workforce and the medical workforce is largely an ageing workforce” and that there is also a “demographic shift to part-time working which means that our numbers are completely out of kilter, both medically and nursing-wise. It’s difficult [because] you might have a full-time consultant retiring or a full-time nurse retiring, but you’re unlikely to get a full-time person to replace them.”⁸⁶

Dr Subarna Chakravorty said that “a generation of highly trained, highly specialised, very effective and hard-working nurses are probably coming to their retirement age now, and we are going to be in a huge, huge hiatus unless we are skilling up the next generation of specialist nurses”.⁸⁷

Specialist sickle cell nurses spoke of the importance of succession planning on a national level. One told us that “succession planning is not properly thought about” and “there will not be enough appropriately trained nurses to care for the patients unless something is done about it”.⁸⁸ Another said that specialist sickle cell nursing workforce levels “will not grow without investment and the recognition of how important they are to patients’ lives and positive outcomes.”⁸⁹ Andy Houghton argued that this preparatory work needs to take place “ten years before we need them” to ensure there is time for it to be implemented.⁹⁰

80 SY, written evidence [full name withheld by request]

81 Stephanie George, written evidence

82 British Society for Haematology, written evidence

83 NHS Race and Health Observatory, written evidence

84 RPP Group UK, on behalf of Terumo BCT, written evidence

85 Kim Newell, interview, Tuesday 20 June 2023

86 Dr Josh Wright, interview, Tuesday 23 May 2023

87 Dr Subarna Chakravorty, interview, Friday 21 April 2023

88 Anonymous, written evidence [name withheld by request]

89 Anonymous, written evidence [name withheld by request]

90 Andy Houghton, interview, Wednesday 26 April 2023

WHAT IS THE IMPACT OF SPECIALIST SICKLE CELL NURSING WORKFORCE SHORTAGES?

Over the course of our inquiry, we heard that the shortage of specialist sickle cell nurses has a profound impact on patients and their carers, but also on specialist nurses and their clinical colleagues. These impacts are interlinked, with stressed and overworked clinicians unable to provide care to the standard they would like, which contributes to the care failings patients encounter.

Impact on patients and carers

The shortage of specialist sickle cell nurses means that patients' care is frequently impacted by encountering nurses who do not have sufficient knowledge of sickle cell to deliver a good standard of care.

“The lack of community and day care staff can lead to chance of early intervention being missed and clinical situations escalating.”

– North Central London and East of England Haemoglobinopathies Coordinating Centre

The British Society for Haematology summarised the impact of nursing workforce shortages: “Patients get very poor quality care and patient experience is worsened. Corners are cut and a very basic level of care is provided, which may lead to reduced patient engagement with healthcare, poor adherence to treatment and appointments, worsened health

outcomes and wasted opportunity for the NHS to improve health outcomes.”⁹¹

The NHS Race and Health Observatory said that many patients choose to self-medicate and view hospital as a “last resort” due to poor experiences with ambulance care and in Emergency Departments, but noted: “Where patients can directly access care by sickle cell nurses or similar specialist care teams, this can completely change their experiences for the better.”⁹²

One patient told us that they had “great” care from the specialist sickle cell team but that it “can be impacted by the limited resources and the amount of time they have to deal with all the patients”. They told us that their experience of receiving care from non-specialists was much worse, citing experiences including not receiving pain relief within the recommended 30 minute timeframe, insufficient observations and exposure to inappropriate temperatures. The result of this is that, if the specialist team are not available, “I will have a tendency to stay at home, suffer in silence and try and manage my symptoms on my own. This can

91 British Society for Haematology, written evidence

92 NHS Race and Health Observatory, written evidence



and has exacerbated my symptoms and conditions, making the road to recovery prolonged and more challenging.”⁹³

“Understaffing is a serious issue even if it affects a single shift. One may think that this wouldn’t affect patients except occasionally, but it affects their care at all times. I wouldn’t want to have a patient on a ward if their care wouldn’t be adequately supported at all times during their care journey. However, sometimes, I have had no choice.”

– Dr Thomas Lofaro, Consultant Haematologist,
London North West Healthcare NHS Trust

Richard Patching described repeated failures to ensure appropriate information about his wife Carol’s condition is passed on when she is transferred between wards, leading to care failings including exposure to inappropriate temperature and a lack of fluids being provided. While noting that transfer of information between wards is not a problem specific to sickle cell, he pointed out that “if the hospital had enough nurses with basic knowledge of sickle cell care then that information would not need to be transferred”.⁹⁴

Stephanie George said that often when she is in hospital the nursing care she receives is from agency nurses. As they are not embedded in the hospital and its processes, this often leads to delays in receiving medication “as they may not know where the medication is stocked, or cannot access the computer as they do not have a log-in, or they have to wait for a nurse that works on the ward to check medication with them”.⁹⁵

93 Claire T, written evidence [full name withheld by request]

94 Richard Patching, written evidence

95 Stephanie George, written evidence

“Our loved ones know there is lack of staffing in hospitals, plus with the lack of understanding and support offered to us, they worry about us when we are in hospital. They reflect on cases like Evan Nathan Smith and this causes a lot of anxiety.”

– Sickle Cell Suffolk

Abi Adeturinmo also highlighted delays in receiving pain relief medications and said that the poor care she has received as a result of insufficient nursing support means that she “[tries] not to go to the hospital when in sickle cell crisis unless it is life-threatening, due to the previous traumatic experiences of poor hospital care”.⁹⁶

Araba Mensah, whose daughter has sickle cell, commented on a lack of ‘hands-on’ nursing, so “patients who have difficulties, for example feeding themselves or with personal hygiene are left to suffer unattended”. It is also difficult to get information, she told us: “They are not able to give you an update on your child’s condition or progress or answer your queries. The response is always, ‘I’m not your child’s named nurse, but the one looking after her is unavailable’ or, ‘I will call a doctor for you’, but of course during the visiting time, the doctor never comes.”⁹⁷

Specialist nurses and other clinicians also recognised the effect of workforce shortages on patients. As a way of ensuring patients receive appropriate care when accessing Emergency Departments, one Consultant Haematologist said it is important for specialist sickle cell nurses to be present, “making sure they’re getting the pain relief, monitoring their pain and making sure the nurses on the wards and on A&E know how to monitor appropriately”.

However, they told us, “ours haven’t been doing this a lot because they’ve just been stretched”, meaning patients do not have access to this crucial support in the Emergency Department.⁹⁸

Kim Newell said that workforce shortages prevent specialist sickle cell nurses from having the time to engage with patients, to “sit down and really talk to find out what some of their problems are, the reason why they’ve come into hospital. I think that is really missing, because you hear so much about what the issues are and then you know how to better deal with them ... they need the input and they’re not getting it. It’s not because we don’t want to, we just don’t physically have the time to do that”.⁹⁹

Another nurse cited the tragic case of Evan Nathan Smith, who died in 2019 as a result of care failings and understaffing. She said: “His untimely death was so devastating because appropriate measures could have been put into place to prevent it. Sadly, I believe this may happen to other patients with sickle cell.”¹⁰⁰

Dr Martin Besser and Raeesa Aaturally, who work together providing sickle cell care at Cambridge University Hospitals NHS Foundation Trust, told us that patients miss out due to a lack of capacity for the specialist sickle cell service to engage in proactive outreach. Dr Besser noted that they had recently held a virtual patient evening but “not many patients dialled in” and with more capacity they could reach out to patients in advance. Raeesa added: “That’s especially the bit that young adults with sickle cell need; they need someone to still troubleshoot them and nag them. The NHS is based on you handling your own affairs: you get given an appointment; they expect you to take it up. If you don’t take it up, it’ll be 18 months before you get another one. That’s a really big issue, and our sickle cell patients struggle with that.”¹⁰¹

Delays in accessing transfusions due to a shortage of nurses were also reported. Terumo BCT said that sickle cell patients “wait hours or sometimes overnight [for emergency transfusions] due to the lack of nurses in the centre, leading to poor care and

96 Abi Adeturinmo, written evidence

97 Araba Mensah, written evidence

98 Anonymous, interview [name withheld by request]

99 Kim Newell, interview, Tuesday 20 June 2023

100 SY, written evidence [full name withheld by request]

101 Dr Martin Besser and Raeesa Aaturally, interview, Monday 26 June 2023

outcomes for sickle cell patients”.¹⁰² Patient Yvette Hendricks told us she “often can’t get my transfusion appointment at the right time [which means] waiting while my haemoglobin is falling, causing me to get tired and breathless”.¹⁰³

We were told of the allowances patients have to make in the expectation that they will receive inadequate care. Bernadette Hylton said: “The patients are aware that the staffing crisis is a real issue and are generally understanding. This should not be their priority of things to worry about when they are unwell. Worryingly, they will often delay attending the Emergency Department if they are unwell as they know they will not receive adequate care, often waiting until they can be triaged in-hours by a [specialist sickle cell nurse] or be booked into the day unit for review.”¹⁰⁴

Another example came from Lynette, who told us that, due to the regional variation in workforce levels described above, she and her husband had “stipulated that [their children who have sickle cell disorder] ... had to stick to the big urban places” when applying to university, and that they first researched the level of sickle cell service provision in each place they were considering.¹⁰⁵ While undoubtedly a less serious impact on sickle cell patients than experiencing direct care failings, the fact that sickle cell patients have their options in life limited in this way is an evidently unacceptable situation.

102 RPP Group UK, on behalf of Terumo BCT, written evidence

103 Yvette Hendricks, written evidence

104 Bernadette Hylton, written evidence

105 Lynette, interview, Tuesday 13 June 2023 [full name withheld by request]



Nurses and their clinical colleagues told us that understaffing has a significant impact on them and the care they are able to offer, whilst emphasising that the effects of this are most keenly felt by patients themselves.

Impact on clinicians and the care they provide

Understandably, some sickle cell patients felt that the impact of workforce shortages on nurses themselves was not something they were in a position to consider. Lowlah Bloom told us: “I’m not geared to the impact it has on nurses as it’s a privilege to be able to choose your profession and leave if it’s not working. We don’t get the same privilege [as] a patient to up and leave. So I haven’t had the privilege of thinking about their impact or how it affects them.”¹⁰⁶

However, other patients and patient carers did acknowledge the impact on nurses and their clinical colleagues. Yvette Hendricks noted that nurses she encounters are sometimes “stressed and overworked.”¹⁰⁷ Laurel Brumant-Palmer said: “Having a lack of specialist trained nurses not only puts pressure on existing staff who are doing an amazing job, but this is also causing the specialist staff to be overworked, unappreciated and devalued.”¹⁰⁸

Others noted that the impact on nurses and on patients are interlinked. One patient described a recent visit to hospital where staff were “looking tired”, with “low morale” and “some of the nurses actually shared their frustrations and apologised, explaining the lack of staff meant there was more

pressure and workload for them. They did not even have time for breaks. This is clearly not conducive to [a good experience for] them or us as patients in their care.”¹⁰⁹

“The current level of nurse staffing could mean the difference between life and death for sickle cell patients.”

– Sekayi Tangayi, specialist sickle cell nurse

Stephanie George told us: “I feel sorry for nurses at times because the pressure they are under is a lot. It must be exhausting being short staffed most of the time, as you know that the patients will feel the effect. I know nurses say that being short staffed affects the care they give to patients, as they can’t always give the care the patients deserve.”¹¹⁰

Nurses and their clinical colleagues told us that understaffing has a significant impact on them and the care they are able to offer, whilst emphasising that the effects of this are most keenly felt by patients themselves.

106 Lowlah Bloom, written evidence

107 Yvette Hendricks, written evidence

108 Laurel Brumant-Palmer, written evidence

109 Claire T, written evidence [full name withheld by request]

110 Stephanie George, written evidence

One specialist sickle cell nurse said workforce shortages cause “low morale when we don’t have enough time to do our jobs or the time we do have is spent doing more managerial work or covering staff sickness [rather than being] able spend quality time with the patients”.¹¹¹ Another described often feeling that her role as a specialist sickle cell nurse involves “just going around the clock trying to keep your head above water and to catch up with everything”.¹¹²

“The current level of staffing frustrates both staff and patients as the treatment need is not met. This leads to more friction between nurses and patients, further stigmatising sickle cell patients.”

– Terumo BCT

Another nurse described the impact of workforce shortages as “very demoralising” and “emotionally draining”, adding, “I aim to take care of all my patients as equally as possible, but when a patient becomes acutely unwell, it is so difficult to provide equal care” due to workforce shortages and the resultant demands of the role.¹¹³

Sekayi Tangayi informed us that she and colleagues will often work out of hours, unpaid to ensure that patients are safe and that the impact of workforce shortages on patients leaves nurses and clinical colleagues feeling “frustrated, concerned and at times anxious”.¹¹⁴

Bernadette Hylton also said that working out of hours is commonplace: “The nursing team, clinicians and managerial teams are frequently working over their contracted hours/at weekends, with no extra pay or visible improvements in sight. Everyone is dedicated to the care of these patients and want to achieve the

best for them. But there is a real threat of burnout and retention issues.”¹¹⁵

A haematology nurse we heard from also highlighted retention issues due to the pressures placed on specialist sickle cell nurses, telling us that “poor staffing levels affects staff retention, and it seems that as the older workforce retires, younger nurses are not staying on the wards long enough to replace them.” Indeed, she herself is leaving nursing: “I am only 24 years old and I have been qualified for less than two years but I do not think it is healthy for me to remain on the wards ... Terrible staffing has impacted my mental health so much and nobody should wake up in dread before work like I so often do.”¹¹⁶

Dr Thomas Lofaro noted that patient-facing staff take the brunt of “justified” anger from patients who experience care failings, which is “often not about the care they have themselves provided, but about the systems they all work within which didn’t serve the patient well”, such as over-booking of clinics and other hospital services. He told us: “Patients have reported occasions to me where staff were under serious pressure and stress, and the patient feedback was that this didn’t help their care because they were themselves in pain, stressed and worked up”.¹¹⁷

The British Society for Haematology highlighted that, in addition to causing “overwork, work-related stress and absenteeism” among nurses themselves, the shortage of specialist sickle cell nurses also impacts Consultant Haematologists, who are forced into “spending additional time dealing with requests that are more suitable for nurses, thereby taking them away from consultant duties, adding to their workload and job dissatisfaction”.¹¹⁸

Evidently, the current level of specialist sickle cell nursing workforce is failing both patients and staff.

111 Anonymous, written evidence [name withheld by request]

112 Anonymous, interview [name withheld by request]

113 SY, written evidence [full name withheld by request]

114 Sekayi Tangayi, written evidence

115 Bernadette Hylton, written evidence

116 SY, written evidence [full name withheld by request]

117 Dr Thomas Lofaro, written evidence

118 British Society for Haematology, written evidence

WHY ARE THERE TOO FEW SPECIALIST SICKLE CELL NURSES?

There are a range of factors that mean there are too few specialist sickle cell nurses. There is a lack of funding for specialist sickle cell nurse posts but also too few nurses wanting to specialise in sickle cell. The two problems reinforce each other and ensure that the situation continues.

Funding and lack of prioritisation by healthcare leaders

Funding for specialist sickle cell nursing posts is seen as harder to secure than for other types of nursing positions. One specialist sickle cell nurse said that when you look at other health conditions, “you’ve got another nurse, you’ve got another nurse, you’ve got a physio, you’ve got a pharmacist. Well, why is there never any money when it comes to us? ... It just seems to be a shut door every single time.” She told us that it seems funding only becomes available in response to crises such as the ones cited in the *No One’s Listening* report but that such crises could be avoided if funding was put in place earlier.¹¹⁹ Nkechi Anyanwu made the same point, telling us that more specialist sickle cell nurses are needed and “we don’t have to wait for things to go wrong before we address them”.¹²⁰

Describing the history of “chronic underinvestment” in sickle cell services, Dr Subarna Chakravorty told us that this was due to sickle cell being overlooked by healthcare commissioners who have failed to give due regard to the condition. She argued that it is only following “shocking” examples of care failures such as Evan Nathan Smith’s death and subsequent calls for change from the sickle cell community that health system leaders are starting to pay attention to sickle cell, but that there is still further to go in addressing past underfunding.¹²¹

There has been a welcome increase in funding for specialist sickle cell nurses in some areas of London through the London Sickle Cell Improvement Programme (established following work undertaken by NHS England in the wake of *No One’s Listening*); however, the funding is non-recurrent which may lead to service disruption further down the line if further funding is not provided. Other areas of the country have not benefited from similar funding increases. There is therefore also a risk that regional disparities will only be further exacerbated without similar increases in other areas of the country.

Often, the lack of funding is connected to under-prioritisation of sickle cell among healthcare leaders and management. One specialist sickle cell nurse said that many in leadership positions “are not aware of haemoglobinopathies, or have not looked after patients with haemoglobinopathies”, which affects the extent to which they see it as a priority.¹²²

During the course of developing this report, we were made aware of an example of a funding application that was rejected despite being demonstrably effective. The Sickle Cell Analgesia Protocol Evaluation (SCAPE) trial led by Professor Paul Telfer found that there was improved patient satisfaction when sickle cell patients who presented at Emergency Departments were supported by

119 Anonymous, interview [name withheld by request]

120 Nkechi Anyanwu, focus group at STANMAP meeting, Thursday 29 June 2023

121 Dr Subarna Chakravorty, interview, Friday 21 April 2023

122 Anonymous, written evidence [name withheld by request]

a specialist nurse. Following these findings, the Acute Sickle Pain Sub-Group of the National Sickle Pain Group established by NHS England made an application for NHS Innovation funding for ten

dedicated specialist nurse roles supporting sickle cell patients in Emergency Departments. The application was unsuccessful, meaning patients continue to lack the support they need in Emergency Departments.

Perceptions of sickle cell as an undesirable specialism

Among nurses, sickle cell is often not seen as a desirable area to work in. We were told that sickle cell “has historically been seen as challenging and complex” and “is not seen as a ‘sexy’ area of specialisation for health professionals”.^{123 124}

In some respects, it is understandable that people may not wish to specialise in sickle cell. As Dr Subarna Chakravorty pointed out, “Junior nurses who are looking to specialise, maybe see how overworked the senior nurses are and go, ‘Well, I don’t want to be spending my life doing this because what’s the point? I could be doing cancer, I could be doing CAR T-cells or whatever’.”¹²⁵

123 Sekayi Tangayi, written evidence

124 Elizabeth Blankson-Hemans, written evidence

125 Dr Subarna Chakravorty, interview, Friday 21 April 2023



However, we also heard that sometimes prejudicial attitudes affect perceptions around the desirability of working with sickle cell patients. Carol Burt said that “because historically sickle cell is seen as a ‘Black people issue’ there may be an element of racism involved in selecting haemoglobinopathies, particularly sickle cell, as an exciting career path”.¹²⁶

Bernadette Hylton told us that there “there is still a heavy overshadowing of racist and outdated opinions towards individuals with sickle cell” which

“deters many in progressing in careers focused on sickle cell”.¹²⁷

The North Central London and East of England HCC argued that this type of prejudice can also be found among those in senior positions, telling us that “racist attitudes persist in the NHS and these can be perpetuated by senior leaders within clinical hierarchies leading to red cell disorders being considered a second class or lesser career compared to malignant disorders”.¹²⁸

Insufficient training and experience in sickle cell

Insufficient training in sickle cell and a lack of exposure to sickle cell patients in the early years of nurses’ careers also influence the number of nurses who choose to specialise in sickle cell. While there has been increased recognition of the need for improvement in the delivery of sickle cell care in the aftermath of *No One’s Listening*, there has yet to be appropriate action on improving nurse training in sickle cell.

Many patients raised the lack of sickle cell training for nurses and the British Society for Haematology highlighted the lack of sickle cell teaching in undergraduate curricula and insufficient postgraduate training opportunities.¹²⁹ The NHS Race and Health Observatory told us that “it is unacceptable that not all nursing and medical schools provide practical training, resources and lectures for trainees and qualified nurses for this condition”.¹³⁰

Once nurses qualify, there is a lack of opportunities for sickle cell training. We heard from a haematology nurse that regular sickle cell training is not provided in their NHS Trust, but that it is for malignant haematological conditions (such as leukaemia, lymphoma and myeloma) and that “this contributes to

the subsequent neglect we see among sickle cell as a condition”.¹³¹

Dr Subarna Chakravorty also noted that there is “very little in the way of training available” for nurses looking to specialise in sickle cell and that existing specialist sickle cell nurses are often so busy that they do not have time to offer mentoring to others.¹³²

Dr Martin Besser told us that sometimes people are put off working with sickle cell patients due to ongoing stigmatising attitudes borne out of a lack of exposure to sickle cell patients. However, he pointed out that he had “never met a nurse who didn’t like looking after sickle patients once you get to know them ... it actually brings out the best in your nursing skills, in terms of what these patients actually need”.¹³³ Evidently, if more nurses were able to gain this experience during training or in the early years of their career, more may choose to specialise in the condition.

126 Carol Burt, written evidence

127 Bernadette Hylton, written evidence

128 North Central London and East of England Haemoglobinopathies Coordinating Centre, written evidence

129 British Society for Haematology, written evidence

130 NHS Race and Health Observatory, written evidence

131 SY, written evidence [full name withheld by request]

132 Dr Subarna Chakravorty, interview, Friday 21 April 2023

133 Dr Martin Besser, interview, Monday 26 June 2023

Lack of opportunity for career progression and unclear career pathways

A lack of opportunity for career progression can also serve to deter nurses from specialising in sickle cell. We heard that the limited number of posts available in sickle cell care compared to other areas mean that there are fewer options for career progression and development.¹³⁴

NHS roles and salaries are separated out into different 'bands', with newly-qualified nurses starting at Band 5, rising to the most senior nursing positions (often consultant roles) at Bands 8 and 9. Sekayi Tangayi told us that in sickle cell, the majority of specialist roles are "downplayed" at Band 6 or 7 and that there are only two sickle cell consultant nurses in the whole country, meaning "if you are a student nurse, why would you aspire to work in sickle cell if you already know that your career will end at band 6/7?"¹³⁵ Likewise, Carol Burt said that "many other specialist nurses potentially can be on a higher rate/band delivering similar specialist care" for other conditions.¹³⁶

We were also told by specialist sickle cell nurses that the career pathway can be confusing to those looking to enter it. Nkechi Anyanwu asked: "When does a nurse become an Advanced Nurse Practitioner? What are the skills you need to arrive at that point, and if you are a sickle cell nurse doing genetic counselling, when do you become a senior counsellor? These are issues people ask [about] when they're coming into the field. That progression is so unclear, you could be a nurse specialist for so many years without any progression".¹³⁷

Helen Murphy pointed out that there are many different job titles for specialist sickle cell nurses, despite them doing the same or very similar roles and that "that can be quite confusing" for people looking at a career in sickle cell.¹³⁸ This was backed up by another specialist sickle cell nurse who noted that "many years ago there was some work done around titles for nurses and there was about 40 different titles that the nurses used, whether it was acute CNS, CNS acute, acute haemoglobin", and argued "we need to start by narrowing down the title" to make it easier for people to understand career progression.¹³⁹

Sekayi Tangayi said that the problem is beyond just the variety of job titles, but also the lack of standardised national job descriptions. Noting that this is standard practice for nursing posts in other health conditions, she argued that specialist sickle cell nursing post job descriptions are often unclear to people looking to understand what the role will entail, asking rhetorically: "Do we want them to do clinical work? Do we want them to do genetic counselling? Do we want them to have an aspect of community care joined together with hospital care?" Given this, she told us, a piece of work should be undertaken to understand the various jobs people are currently doing and what standardised job descriptions should look like for each band level.¹⁴⁰

¹³⁴ North Central London and East of England Haemoglobinopathies Coordinating Centre, written evidence

¹³⁵ Sekayi Tangayi, written evidence

¹³⁶ Carol Burt, written evidence

¹³⁷ Nkechi Anyanwu, focus group at STANMAP meeting, Thursday 29 June 2023

¹³⁸ Helen Murphy, focus group at STANMAP meeting, Thursday 29 June 2023

¹³⁹ Anonymous, focus group at STANMAP meeting, Thursday 29 June 2023

¹⁴⁰ Sekayi Tangayi, focus group at STANMAP meeting, Thursday 29 June 2023

WHAT NEEDS TO HAPPEN TO ADDRESS THE SPECIALIST SICKLE CELL NURSING WORKFORCE SHORTAGE?

There is a clear consensus among sickle cell patients, carers and healthcare professionals that the current specialist sickle cell nursing workforce level is insufficient. As part of our project, we sought experts' opinions on what would constitute an adequate level of specialist sickle cell nursing workforce and, crucially, what needs to happen to get there.

Defining and mandating a minimum specialist nurse/patient ratio

There is currently no formal standard specifying a safe specialist nurse/patient ratio for sickle cell. While the National Peer Review Programme for sickle cell gathers data on the number of patients being managed by Consultant Haematologists, no such data is gathered for specialist nurses.

“Unfortunately in the peer review standards, there is nothing in terms of numbers for the nurses per patient. We have that for consultants, we have that for psychology, but we don't have that for nursing.”

– Dr Kofi Anie MBE, Consultant Psychologist,
London North West University Healthcare
NHS Trust

Identifying the right nurse/patient ratio is challenging and many of those we heard from emphasised this, noting that a simple numerical figure can fail to take account of the complexity of the care each patient requires or the other services patients have access to, for example. One specialist sickle cell nurse told us: “If you have a stable cohort then fewer nurses will be required. If you have lots on transfusion programmes, frequent admissions or chronic complications then they require much more nursing time.”¹⁴¹

Nevertheless, there was strong backing for developing a formal national standard on a safe specialist nurse/patient ratio. Dr Subarna Chakravorty argued that “we need a ratio” and that this would provide those working in sickle cell care with the backing they need to persuade healthcare managers to provide safe staffing levels, because “we can go to them and say, ‘Well, we are not meeting national standards’”.¹⁴²

We had a range of responses to our request for recommendations on what the ratio should be of number of sickle cell patients per specialist nurse

¹⁴¹ Anonymous, written evidence [name withheld by request]

¹⁴² Dr Subarna Chakravorty, interview, Friday 21 April 2023



employed. When taken in the aggregate, and as the most common ratio cited, we believe a consensus ratio to be a minimum of one specialist sickle cell nurse per 100 registered sickle cell patients registered with the service. NHS England's ongoing review of sickle cell service specifications is a good opportunity to introduce a minimum specialist nurse/patient ratio.

Recommendation: NHS England to develop a national standard for a minimum specialist nurse/patient ratio that must be met by each Haemoglobinopathies Coordinating Centre region.

Recommendation: NHS England's national standard outlining the specialist nurse/patient ratio should be for a minimum of one specialist sickle cell nurse per 100 registered sickle cell patients registered with the service.

Recommendation: NHS England to direct that the nurse/patient ratio should be commissioned and implemented on a proportional basis i.e. under a one-specialist-nurse-per-100-registered-patients ratio, a service with 25 patients would be required to employ a specialist nurse to cover sickle cell on a 0.25 working time equivalent (WTE) basis.

Increasing and making best use of funding for sickle cell services

Sickle cell services have suffered decades of neglect and underfunding. As outlined in earlier sections of this report, we heard from all parts of the sickle cell community that there is not enough funding for specialist sickle cell nursing roles and that is harder to secure funding for these posts than for other health conditions.

While increased funding is not the whole answer – with action also needed to ensure there are people ready and willing to fill vacant posts – it is a necessary part of addressing the problem. Among those advocating increased funding, we were told that there needs to be work undertaken by commissioners to look at current service provision and demand to then decide on how to increase

staffing levels.¹⁴³ We also heard that increased funding for haematology must include a ringfenced amount for sickle cell services.¹⁴⁴

We were told that there is a need for greater flexibility in allocating funding to respond to opportunities as they arise. Dr Josh Wright outlined an example of an Advanced Nurse Practitioner in his hospital who had approached him about joining the sickle cell service. Often, when actively trying to recruit, Dr Wright said he would “put in lots and lots of work and I would get no applicants just because it’s a niche area”. As he told us in respect of the Advanced Nurse Practitioner, “You don’t find people coming like that very often, so you have to take this opportunity”. At the time of speaking to us, he was building an opportunistic

143 Sekayi Tangayi, written evidence

144 Carol Burt, written evidence



business case but “this now involves a series of debates with hospital management to convince them that this is money well spent and it might be over our budgets, but in the long run it’ll make the service much more robust”.¹⁴⁵ In order to ensure a consistently good standard of care for sickle cell patients, it is crucial that commissioners recognise the importance of providing funding at opportune moments.

This flexibility in funding must be on top of a sustainable baseline, however. Specialist sickle cell nurse Keisha Osmond-Joseph noted that there has been increased attention to sickle cell in the past two years, with well-publicised instances of care failings, new therapies and increased awareness campaigns. However, previous “peaks and troughs” in funding for sickle cell services have “create[d] barriers and constraints to sustain many innovations, developments and transformations which have been established over the years, ultimately leading to unsustainable service delivery and poor long term quality of care.”¹⁴⁶ Guaranteed ongoing funding is necessary to ensure services have the certainty required to recruit specialist sickle cell nurses, knowing that they will be able to sustain funding for the role.

As well as delivering funding to expand the specialist sickle cell nursing workforce, we were also told of the importance of providing funding to aid retention of the current specialist sickle cell nursing workforce. Dr Thomas Lofaro said: “It is vital that pressures on staff are addressed and adequately resourced – and this must be with something far better than a token ‘online learning course about sickle cell disease’. We need protected, dedicated staffing, who are adequately paid to reflect their job role, responsibility and dedication, as well as the emotional requirements of the position.”¹⁴⁷

One nurse noted the importance of funding for nurses’ pay, telling us that “a key factor in resolving the extremely poor nurse staffing levels (particularly for sickle cell care) is by providing a liveable wage for nurses. The pay for nurses is low and does not reflect the high level of inflation”.¹⁴⁸ Ensuring nurses receive a fair wage that reflects ongoing cost-of-living pressures is another key aspect of delivering an adequate level of specialist sickle cell nursing workforce.

As well as the undoubted need for increased funding, we were presented with examples of how existing funding could be used in a more efficient way. As outlined earlier in the report, in some areas there is a lack of cohesion in commissioning arrangements between community settings and acute settings. One specialist sickle cell nurse argued that it may be more efficient to replicate how other chronic long-term conditions tend to be organised, with each area having a ‘hub’ that hosts all of the relevant healthcare workers for that condition.¹⁴⁹ Ensuring a more cohesive approach to commissioning and delivering sickle cell services is likely to lead to a more effective use of existing resources.

Recommendation: NHS England to undertake a review of current national sickle cell workforce provision to assess where need is greatest, and allocate NHS Long Term Workforce Plan-linked funding for new nursing places accordingly for sickle cell services.

Recommendation: Integrated Care Systems to take a flexible approach to funding new specialist sickle cell nursing roles, ensuring opportunities for recruitment are acted upon when they arise.

Recommendation: NHS England to review how sickle cell nursing roles are currently commissioned across the country, in order to establish a more cohesive approach to sickle cell service commissioning that ensures greater alignment between acute and community-based care.

¹⁴⁵ Dr Josh Wright, interview, Tuesday 23 May 2023

¹⁴⁶ Keisha Osmond-Joseph, written evidence

¹⁴⁷ Dr Thomas Lofaro, written evidence

¹⁴⁸ SY, written evidence [full name withheld by request]

¹⁴⁹ Anonymous, interview [name withheld by request]

Increasing sickle cell training and experience

Currently, the specialist sickle cell nursing workforce is a small pool, with recruitment often involving existing specialist sickle cell nurses moving from one position to another, rather than hiring new entrants to specialist sickle cell nursing.

“There definitely needs to be dedicated funding to increase the workforce, but education about the conditions, and making people aware will also attract health professionals to work in the area.”

– Anonymous specialist sickle cell nurse [name withheld by request]

As outlined in the *No One's Listening* report, there is a need for increased training in sickle cell for nurses and those training to be nurses to improve the care received by sickle cell patients when accessing Emergency Departments and general wards. Such training is also necessary to ensure there is a pipeline of future specialist sickle cell nurses who are knowledgeable about sickle cell and enthused about specialising in the condition.

Ensuring comprehensive training in sickle cell features in the curriculum for those training to be nurses is an essential starting point. There also needs to be repeat training in sickle cell once nurses have qualified and more opportunities for more specialist training opportunities for those interested in specialising in sickle cell care. All of this training should include exposure to working with sickle cell patients to ensure nurses gain hands-on experience in providing sickle cell care.

There was a strong consensus among contributors to our inquiry that there needs to be a single national training model for sickle cell. At present,

there is a variety of local training packages – Sandy Hayes noted that “every HCC is running around ... developing training modules for their local staff”, which she argued should be replaced by one national model as a better use of time and resources.¹⁵⁰ Another specialist sickle cell nurse said there should be a move to a national training package that nurses and centres can then tailor to their particular needs.¹⁵¹

Terumo BCT also backed a standardised national training model for sickle cell care, including for apheresis treatment. They argued that this would “create more capacity to treat [sickle cell] patients as nurses in various centres will be more informed on the needs of patients, as well as the complexities that may arise with transfusions”.¹⁵²

As part of training for those interested in becoming specialist sickle cell nurses, exposure to the varying aspects of sickle cell care is essential. This should include experience of working in both acute and community settings. In acute settings, training should cover providing apheresis procedures and, in the community, those in training should gain experience of providing antenatal counselling and screening and undertaking home visits for newborns, children and adults. Bernadette Hylton told us this would “enable individuals to experience the different areas of care, without potential fatigue before they commit to specialise in one area”.¹⁵³

We heard that secondments and the link nurse role (nurses with an interest in a speciality with a formal link to specialist team members) can also be a useful way to enable nurses to gain this exposure while they consider specialising. Keisha Osmond-Joseph told us link nurse roles “galvanise interest, empower proactive newly qualified nurses and identify those who may want to progress and pursue a pathway to becoming [specialist sickle cell nurses]”.¹⁵⁴

The NHS Long Term Workforce Plan notes the importance of placements in attracting new staff to those specialised services that can find it particularly

150 Sandy Hayes, interview, Thursday 27 April 2023

151 Anonymous, written evidence [name withheld by request]

152 RPP Group UK, on behalf of Terumo BCT, written evidence

153 Bernadette Hylton, written evidence

154 Keisha Osmond-Joseph, written evidence

hard to recruit, specifically citing sickle cell as an example.¹⁵⁵ Increasing sickle cell nursing secondment opportunities and identifying and appointing more link nurses would be a good step towards increasing the pipeline of prospective specialist sickle cell nurses.

Recommendation: Universities, colleges, the Nursing and Midwifery Council and Royal College of Nursing to work with the Sickle Cell Society to ensure that sickle cell features adequately in the curriculum for nurse training courses.

Recommendation: Nursing and Midwifery Council to develop a standardised national training model for nurses training to specialise in sickle cell, which includes gaining practical experience of the full range of sickle cell care.

Recommendation: Haemoglobinopathies Coordinating Centres and Integrated Care Systems to offer shadowing, secondment and link nurse opportunities to those who have expressed an interest in sickle cell care, in line with the NHS Long Term Workforce Plan's emphasis on a flexible approach to career pathways.

Ensuring greater opportunity for progression

Sickle cell is often regarded as an area of healthcare where there is less scope for career progression for specialist nurses than there is for other conditions. Turning around these perceptions so that more nurses see specialising in sickle cell as an attractive career option is key to increasing the specialist sickle cell nursing workforce.

An important first step is for a review to take place into current banding and the competencies and duties required for each level, and for this to be followed by publication of clear parameters to provide clarity on career progression opportunities.

Lara Odelusi, who has worked as a specialist sickle cell nurse, told us that a piece of work along these lines is needed to provide clarity to nurses interested in specialising in sickle cell as to what they can expect the next five or ten years of their career to look like and, "if you come in as a Band 5 or Band 6, where does that lead you and how soon can you make that progression?"¹⁵⁶

We were told that addressing issues around career progression should involve ensuring there are opportunities for specialist sickle cell nurses to "specialise even further" and develop specific skills.¹⁵⁷ Dr Joe Sharif identified training nurses to deliver apheresis procedures as an example of additional

skills that are important for patient care and the wider service.¹⁵⁸

Greater involvement in leadership and management within the sickle cell service is another opportunity to offer career progression for specialist sickle cell nurses. Sandy Hayes advocated "much more engagement and education of the senior nurses in leadership and management, in how to bring teams together, how to keep the programme running".¹⁵⁹ This is another example of a development that would have the dual benefit of providing nurses with opportunity to progress and enhancing the overall service.

Recommendation: NHS England to undertake a review of current banding, responsibilities and job titles for specialist sickle cell nurses, to be followed by publication of clear parameters on the competencies and duties required for each band level, building on the forthcoming Royal College of Nursing publication, *Caring for people with sickle cell disease and thalassaemia syndromes – A competency framework for nursing staff 2nd Edition*.

Recommendation: Integrated Care Systems to provide funding for specialist sickle cell nurses to undertake further training in areas such as delivery of apheresis procedures and leadership and management.

155 NHS England, *NHS Long Term Workforce Plan (2023)*: <https://www.england.nhs.uk/wp-content/uploads/2023/06/nhs-long-term-workforce-plan-v1.2.pdf>. Accessed 3 November 2023

156 Lara Odelusi, focus group at STANMAP meeting, Thursday 29 June 2023

157 NHS Race and Health Observatory, written evidence

158 Dr Joe Sharif, interview, Wednesday 10 May 2023

159 Sandy Hayes, interview, Thursday 27 April 2023

Increasing collaboration and forums for mutual support

Specialist sickle cell nurses often report feeling somewhat isolated in their roles. Increasing collaboration and providing more forums for mutual support are therefore an important part of increasing and retaining the specialist sickle cell nursing workforce.

There are existing structures that are already fulfilling this role. The Sickle Cell & Thalassaemia Association of Nurses, Midwives and Allied Professions (STANMAP) group, for example, provides a useful forum to bring together specialist sickle cell nurses with other colleagues to discuss developments, shared challenges and examples of best practice. However, there is undoubtedly scope for further collaboration and networking.

We heard from one specialist sickle cell nurse that there needs to be “more collaborative working across the country to overcome the feeling of isolation” and that, currently, meetings of nurse forums tend to be focused on particular geographical areas, making it difficult for nurses out of area to attend, and are often advertised without sufficient notice.¹⁶⁰

Sandy Hayes highlighted that in her HCC area, she runs a monthly clinical supervision support group for all of the specialist sickle cell nurses across the HCC because otherwise, “they’re all working on their own”. During the session, nurses from each centre are given the opportunity to provide an update on their work, outlining any challenges they are facing or developments they are leading on.¹⁶¹ The implementation of similar support groups should be adopted by all HCCs as a way of increasing support for specialist sickle cell nurses.

Dr Josh Wright noted that the national reorganisation of sickle cell and thalassaemia services in England has been beneficial in “[bringing] the community together”, with National Haemoglobinopathy Panel meetings and the establishment of a WhatsApp group for sickle cell consultants providing greater opportunity for collaboration.¹⁶² However, both of the examples cited are for Consultant Haematologists; increasing the availability of similar forums for specialist sickle cell nurses would be likely to be similarly beneficial in bringing the community together.

The British Society for Haematology emphasised the importance of nurses being able to attend conferences and meetings and called for bursaries to be made available for them to attend these meetings, and for their employers to allow them to have protected and paid time to attend meetings.¹⁶³

Recommendation: STANMAP to consider diversifying location of meetings and ensure meetings are advertised with sufficient notice.

Recommendation: STANMAP and/or new regional networks to consider establishing new forums for collaboration and support for specialist sickle cell nurses, such as WhatsApp/Facebook groups.

Recommendation: All Haemoglobinopathies Coordinating Centres to establish regular clinical supervision support groups for their specialist sickle cell nurses.

¹⁶⁰ Anonymous, written evidence [name withheld by request]

¹⁶¹ Sandy Hayes, interview, Thursday 27 April 2023

¹⁶² Dr Josh Wright, interview, Tuesday 23 May 2023

¹⁶³ British Society for Haematology, written evidence



Adopting measures to increase specialist sickle cell nurses' capacity

In addition to the need to take measures to increase and retain the specialist sickle cell nursing workforce, we were told that more could be done to make best use of specialist sickle cell nurses' time, ensuring they have more capacity to provide direct patient care.

This partly involves making more use of other NHS staff and associated services. For example, Sekayi Tangayi said that transition nurses based on paediatric wards should play a role in supporting sickle cell patients during the transition from paediatric to adult services, rather than specialist sickle cell nurses taking on this responsibility. She told us that “we need to try not to make sickle

cell and thalassemia too specialist. It needs to be embedded in with what the Trust, the organisation already has”. While she added that this requires transition nurses to be trained in the type of support required by sickle cell patients, making use of existing resources in this way could help to reduce the workload of specialist sickle cell nurses.¹⁶⁴

Dr Josh Wright said that Advanced Nurse Practitioners and physicians' associates can play an important role in delivering clinics alongside specialist sickle cell nurses. Until there is increased funding for specialist sickle cell nurse roles – and time for this funding to take effect – “we have to think of these other professional groups and how they

164 Sekayi Tangayi, focus group at STANMAP meeting, Thursday 29 June 2023

might assist in the delivery of haemoglobinopathy care”.¹⁶⁵

Many experts identified the burden of administrative work on specialist sickle cell nurses. Dr Joe Sharif told us that secretarial support has reduced over time, which means that the specialist nursing team often end up having to support extra administrative work.¹⁶⁶ Ensuring secretarial support is available for sickle cell services offers the opportunity for more direct patient care and is likely to be a more cost-effective use of NHS staff time.

Others advocated greater integration of social workers, youth workers and benefits advisers with sickle cell services, given such work “takes up considerable time from the [specialist sickle cell nurse] clinical workload”.¹⁶⁷

We were also told that improving digitalised healthcare could help to reduce the burden on specialist sickle cell nurses. Dr Thomas Lofaro noted that much of the administrative burden that currently falls on nurses could be automated, citing examples such as automatically identifying patients who need an appointment for their next prescription or a scheduled investigation, prompting the correct bloods tests for the appropriate consultation, pulling results from the patient record that are required for the National Haemoglobinopathy Register and alerting the sickle cell team that a patient with the condition has been admitted.¹⁶⁸

Dr Kofi Anie told us that technology could be utilised to provide greater monitoring of patients at home, noting that this is already happening for other conditions such as for heart failure patients. He argued that this could in time lead to a model where care is centred around a hub with a team of nurses covering a regional area, using technology to monitor patients who would then be visited by nurses as required.¹⁶⁹

An easier-to-implement and particularly urgent example of improving digitalised healthcare is the introduction of uniform digital care plans for sickle cell patients, which also offers the opportunity to better optimise care delivery by sickle cell services and make better use of specialist sickle cell nurses’ time.¹⁷⁰

Recommendation: National Haemoglobinopathy Panel to undertake a review to identify opportunities to make use of other NHS resources to reduce workloads of specialist sickle cell nurses, such as paediatric transition nurses, Advanced Nurse Practitioners and physicians’ associates.

Recommendation: Integrated Care Systems to facilitate greater integration with third sector services and other statutory services to reduce non-clinical workload of specialist sickle cell nurses.

Recommendation: Integrated Care Systems to use new funding for innovative medical technology announced in October 2023 to improve sickle cell services, such as through greater automation of administrative functions and the use of remote digital patient monitoring.

¹⁶⁵ Dr Josh Wright, interview, Tuesday 23 May 2023

¹⁶⁶ Dr Joe Sharif, interview, Wednesday 10 May 2023

¹⁶⁷ British Society for Haematology, written evidence; Helen Murphy, focus group at STANMAP meeting, Thursday 29 June 2023

¹⁶⁸ Dr Thomas Lofaro, written evidence

¹⁶⁹ Dr Kofie Anie MBE, interview, Friday 16 June 2023

¹⁷⁰ NHS Race and Health Observatory, written evidence

CONCLUSION

There are encouraging signs that there has been increased attention to the urgent need to improve sickle cell services in the wake of our last report, *No One's Listening*. Nevertheless, while there has been some positive follow-up action, there remains much to be done.

It is clear from the evidence presented in this report that addressing the sickle cell nursing workforce should be a particularly urgent priority. Our report will be followed by other work in this area. The NHS Race and Health Observatory has commissioned Dr Frédéric B. Piel of Imperial College London to conduct a comparative research project looking at how sickle cell care compares with similar conditions such as cystic fibrosis and haemophilia in order to investigate disparities. The British Society for Haematology will publish a report in 2024 examining shortages in the haematology workforce, including sickle cell, and will set out suggested solutions to what they deem a 'workforce crisis'.

The publication of the NHS Long Term Workforce Plan was also a recognition of the overdue need for action on the NHS workforce. We believe that this report sets out a compelling case for ensuring sickle cell services are prioritised as part of the implementation of the Workforce Plan. Specialist

sickle cell nurses play a crucial role in the care sickle cell patients receive and can have a transformative impact on patients' lives through the wide-ranging care they provide.

As one contributor to this project told us, at the extreme end of the spectrum, they can be "the difference between life and death". *No One's Listening* referred to the tragic deaths of sickle cell patients Evan Nathan Smith and Tyrone Airey, both of whose deaths were avoidable and a result of oversights by insufficiently-trained healthcare professionals. This powerfully demonstrates the importance of having access to care from specialists in the condition.

We urge NHS England and all those we have directed recommendations towards to take action now to ensure all sickle cell patients have access to the specialist care they are entitled to.

ACKNOWLEDGEMENTS

This report was authored by Aidan Rylatt of Principle, working with the Sickle Cell Society on a consultancy basis.

Funding for this project was provided by Pfizer and Terumo BCT. All editorial and managerial decisions were taken independently by the Sickle Cell Society and the report's author.

The report was designed by EPLS Design Ltd.

APPENDIX

The Sickle Cell Society would like to thank all those who provided evidence to the inquiry.

Oral evidence

The following people provided evidence via one-to-one interviews:

- Dr Kofi Anie MBE (Consultant Psychologist, London North West University Healthcare NHS Trust)
- Raeesa Aaturally (Non-Malignant Haematology Specialist Support Nurse, Cambridge University Hospitals NHS Foundation Trust)
- Dr Martin Besser (Consultant Haematologist, Cambridge University Hospitals NHS Foundation Trust)
- Dr Subarna Chakravorty (Consultant Paediatric Haematologist, King's College Hospital NHS Foundation Trust; Chair, Haemoglobinopathies Clinical Reference Group)
- Sandy Hayes (Senior Specialist Nurse, Haemoglobinopathy Service, Oxford University Hospitals NHS Foundation Trust at time of interview, since retired)
- Andy Houghton (Clinical Nurse Specialist, Royal Liverpool and Broadgreen University Hospitals NHS Trust)
- Lynette (parent of two children of young adult age with sickle cell) [full name withheld by request]
- Kim Newell (Lead Nurse, Haemoglobinopathies Children & Adults and HCC Lead Nurse, Barts Health NHS Trust)
- Dr Joe Sharif (Consultant Haematologist, Manchester University NHS Foundation Trust)

- Dr Josh Wright (Consultant Haematologist, Sheffield Teaching Hospitals NHS Foundation Trust; Clinical Lead, North East and Yorkshire HCC; President, British Society for Haematology)

A focus group was held with members of STANMAP (the Sickle Cell & Thalassaemia Association of Nurses, Midwives and Allied Professionals) on Thursday 29th June 2023. The following provided on-the-record quotes featured in this report:

- Nkechi Anyanwu (Community Matron, South East London Sickle Cell & Thalassaemia Centre; Vice Chair, STANMAP)
- Fiona French (Paediatric Haematology Clinical Nurse Specialist, Barts Health NHS Trust)
- Leanne Mawer (Haemoglobinopathy Counsellor, Airedale NHS Foundation Trust)
- Helen Murphy (Paediatric Clinical Nurse Specialist, Noah's Ark Children's Hospital for Wales)
- Lara Odelusi (Quality Improvement Advisor, Camden and Islington NHS Foundation Trust)
- Doreen Richards (Haemoglobinopathy Specialist Nurse, Nottingham University Hospitals NHS Trust)
- Sekayi Tangayi (Consultant Nurse, Sickle Cell and Thalassaemia, North Middlesex University Hospital NHS Trust)

A further two participants in the focus group are quoted in the report anonymously.

Written evidence

The following individuals provided written evidence to the inquiry:

- Abi Adeturinmo
- Anton Bailey
- Dr Martin Besser
- Elizabeth Blankson-Hemans
- Lowlah Bloom
- Laurel Brumant-Palmer
- Carol Burt
- Stephanie George
- Madeleine Glover
- Yvette Hendricks
- Bernadette Hylton
- Dr Thomas Lofaro
- Araba Mensah
- Keisha Osmond-Joseph
- Richard Patching
- Claire T [full name withheld by request]
- Sekayi Tangayi
- Iyamide Thomas
- SY [full name withheld by request]

We received a further four anonymous submissions.

The following organisations provided written evidence to the inquiry:

- British Society for Haematology
- NHS Race and Health Observatory
- North Central London and East of England Haemoglobinopathies Coordinating Centre
- RPP Group UK, on behalf of Terumo BCT
- Sickle Cell Suffolk



SICKLE
CELL
SOCIETY