PARTNERSHIP SOUTHWARK STRATEGIC BOARD

Questions received from the public with responses

MEETING DATE: 5 September 2024

This set of questions was received prior to the meeting taking place. The response document is published on the SEL ICS's website and also emailed to those who submitted the questions. Where a question was raised on behalf of a group, the person's name is listed below; where the person did so as an individual, then their name has not been published.



Working together to improve health and wellbeing for the people of Southwark

Question 1	Please could we have an update on the project NHS South East London is piloting for the care of people in the community with Sickle Cell Disorder across Lambeth, Southwark, Lewisham, Greenwich, Bromley and Bexley.
Response	We've previously published some information on the South East London ICS website about plans to launch a new service to provide greater community support for people with sickle cell disorder in South East London. This will help people of all ages with their physical, mental, and social needs. This is part of a two year pilot programme funded by NHS England across London.
	This service aims to provide personalised and holistic care for people living with sickle cell disorder of all ages in South East London. We're continuing to build the team and expand the service, with specialist care team members joining across South East London. I'll give a brief update on each area.
	More nurses: 'There will be more specialist nurses available for both children and adults with sickle cell. These nurses will work with local NHS trusts'
	 Six additional Sickle Cell Clinical Nurse Specialists have been recruited across South East London to ensure access in every Borough for patients of all ages living with sickle cell.
Continued	• For the Community Sickle Cell team who are based at GSTT, and who cover the Boroughs of Southwark, Lambeth and Lewisham, this has specifically included one additional Paediatric focused Clinical Nurse Specialist alongside an additional adult focused Clinical Nurse Specialist. These nurses will be joining the Community Sickle Cell team who are based Mary Sheridan Centre who already offers services to adults, young people and children with sickle cell disease and thalassaemia and their families. Both of these roles have been recruited to, with the Paediatric focused CNS starting on 9 September 2024.

Response cont. . .

Wider support team: Patients will have access to community-based dietitians, physiotherapists, psychologists, and pharmacists who can help manage your condition.

- All of the four roles the dietician, physiotherapist, psychologist and pharmacist have been recruited to. We were joined by the Dietician and Psychologist in August 2024. They are currently completing their inductions and will start welcoming patients over the next month. This team will be available to meet with and support sickle cell patients of all ages across every Borough in South East London. These four roles will be an extension of the Sickle Cell Community Team that already operates from GSTT and covers Lambeth, Southwark and Lewisham. Referral to the multi-disciplinary team is via the Community Sickle Cell nursing team.
- Patients will be able to access the multi-disciplinary team via one location which will either be based in Southwark, Lambeth or Lewisham. Discussion is progressing with a number of venues
- When patients come to meet the multi-disciplinary team, they will have the opportunity to meet with some or all of the clinicians depending on individual patient needs. Because this is a new service we are looking for patient feedback to guide us on the best way for our team to meet patient needs. Therefore, the appointments may change based on this feedback. We are aiming to launch a Let's Talk page on the South East London ICS website during September, and patients, carers and their families will have an opportunity to complete a survey about sickle cell community services, alongside letting us know if they wish to be involved in some workshops to discuss care for people living with sickle cell and how we could continue to make our community services better.

Help with everyday life: 'The service can offer welfare advice and support on benefits and legal matters.'

- Welfare support is available for all patients, carers and their families living with sickle cell disorder across South East London. As part of the Community Sickle Cell team who are based at GSTT, a Welfare Support Advisor is available. Referral to the Welfare Support Advisor is via the Haematology team based at the hospital and/or Community Sickle Cell Nursing Team.
- We have also partnered with Southwark Law Centre to provide further specialist welfare benefits advice through a dedicated Welfare Rights Caseworker covering South East London. Referral to Southwark Law Centre is via the Haematology team based at the hospital and/or Community Sickle Cell Nursing Team.
- Referrals are being accepted to both the Welfare Support Advisor and Welfare Rights Caseworker patients can speak to their healthcare team to let them know they are interested in speaking with either of them.

Response cont. . .

Peer support: Young people with sickle cell can connect with others who understand what they're going through, through the Sickle Cell Society.

- The Peer to Peer Mentoring Programme, run by Sickle Cell Society, has been taking referrals for South East London sickle cell patients aged between 10-24 years old since January 2024.
- In July 2024, 51 referrals had been made to the programme in South East London.
- The sessions are undertaken on a one-to-one basis, and mentee's will be connected with a mentor who also has sickle cell disorder. These mentoring sessions can take place online and F2F depending on what would work best for the mentee and mentor.
- The aim of the Sickle Cell Children & Young Person's Peer Mentoring Programme is to improve the health and wellbeing of young people with SCD through training, emotional support from mentors and peer-support, improve young people's understanding and management of the condition, improve young people's ability to negotiate transition from paediatric to adult services, encourage young people's involvement in volunteering to support others with the condition and engage more with their local community.
- Referrals can be made via the patient's Haematology team based in the Hospital or in the Community, but self-referral to the programme is also possible via the Sickle Cell Society website.
- The programme in South East London is also supported by a clinical lead, a Consultant Haematologist, based at GSTT.

Education and information: 'There will be new resources to help patients, schools, workplaces, and healthcare professionals learn more about sickle cell disorder.'

We have yet to initiate our education and information part of the project. Once the service is fully set up and running, we will be inviting residents of South East London living with sickle cell disorder, parents and carers, to let us know what education and resources would be most beneficial for them.

Question 2 I spoke in the past at one of these gatherings about the prevalence of AF and Stroke among the Afro Caribbean segment of the community in Southwark. Is there any development on Health related aspect specifically to the care of these individuals? Our latest figures show there are over 3,300 people registered with a Southwark GP that have been diagnosed with atrial fibrillation. Of these 580 are from a Black ethnic background. There are over 3,800 people who have been diagnosed with stroke, of which 1,330 are from a Black ethnic background. To improve the early identification of residents with these and other cardiovascular conditions the NHS healthcheck programme offers a free healthcheck to residents aged 40-74. Last year over 7,600 healthchecks were provided, with almost two thirds of these among residents from a minority ethnic background. In previous years there have been a number of campaigns to improve public awareness of the risk factors for stroke including atrial.

In previous years there have been a number of campaigns to improve public awareness of the risk factors for stroke including atrial fibrillation. Promotion of pulse rhythm check by clinicians at all contacts has also been a key feature of long-term condition reviews in primary care and this has improved the detection of the AF. Including this feature in the vital 5 checks would be good to consider.

Southwark residents experiencing symptoms of stroke should be able to access emergency treatment via our two local acute trusts. Kings College Hospital is a hyper-acute stroke unit where emergency interventions will be offered to minimise the impact of stroke. We also have extensive community rehabilitation teams for this condition. As with any NHS or care service, it is important that residents of all backgrounds are cared for in a culturally competent and personalised way.

