Sickle Cell Enhanced community service

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Introduction and Context

Sickle Cell Disease (SCD) is the most common genetic condition in England, **affecting 17,000 people in England, mainly affecting Black African & Caribbean communities**. It is a serious and potentially life limiting and causes episodes of severe pain, and requires lifelong management with specialist care.

The All-Party Parliamentary Group on Sickle Cell and Thalassaemia and the NHS Race Observatory's "No One's Listening" report 2021 found that:

- There is lack of staff training leading to misdiagnoses and inadequate or delayed pain relief.
- People with SCD report negative attitudes often underpinned by racism.

Population health

South East London has the largest SCD patient population in the UK (~3,000 people).

Health inequalities

People with sickle cell disease have experienced longstanding health inequalities.

We are collaborative • We are caring • We are inclusive • We are innovative

SEL Sickle Cell improvement programme

Networked approach to community services

Multi Disciplinary (MDT) coverage and borough-specific services.

Peer support & patient experience

How mentoring improves care and lived experiences.

Emergency & urgent care

ED bypass models & improved hospital pathways.

Workforce & Awareness

NHS staff training campaigns (ACT NOW) and co-produced e-learning module.

The enhanced community service

Enhanced sickle cell community service

This model expands support for children and adults with SCD by increasing Community Nurse Specialists (CNS) and adding 13 WTE staff to a broader multidisciplinary team providing equitable access across South East London.

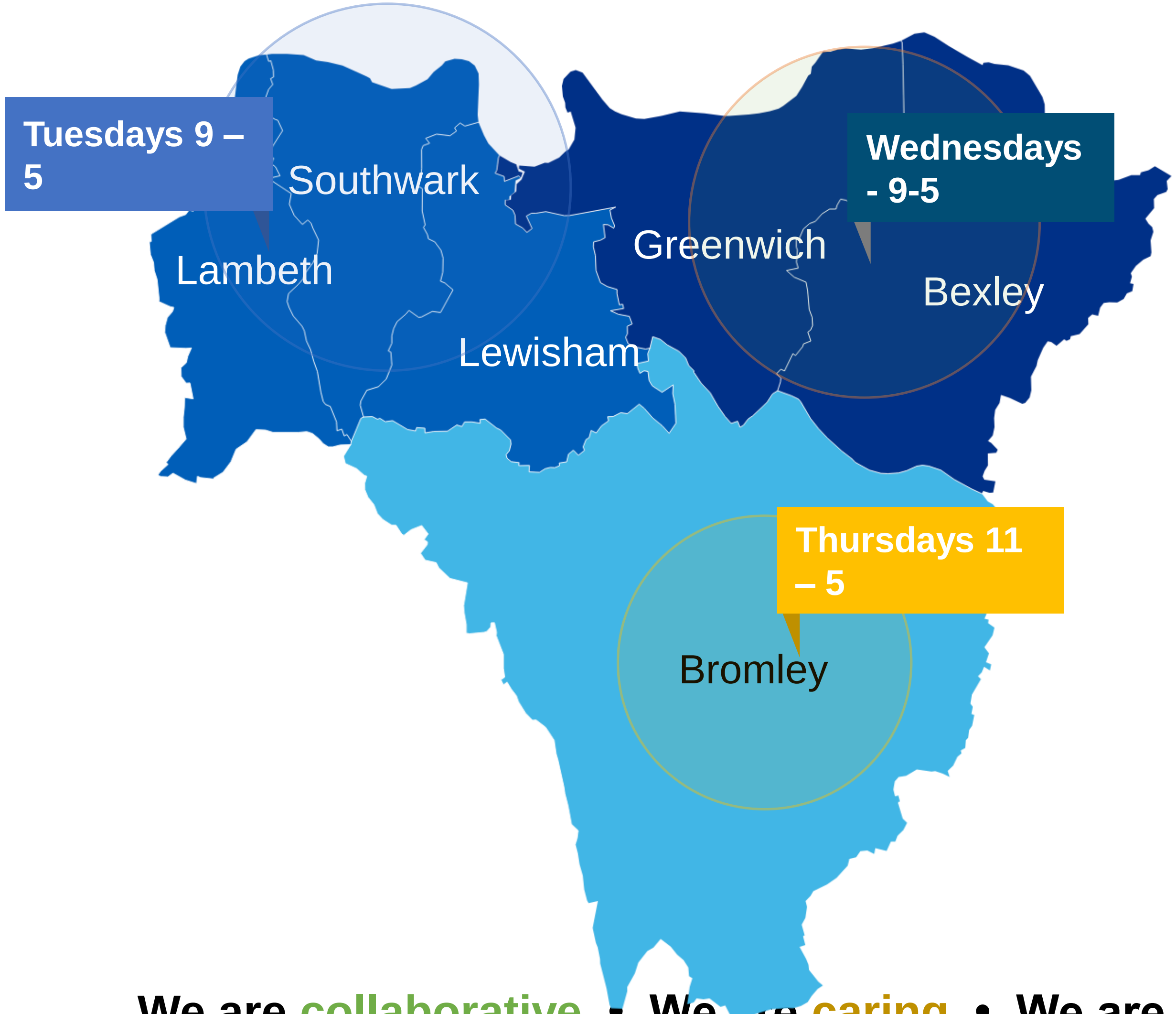
Patients now have one-stop access to a dietitian, physiotherapist, and pharmacist at three SEL community clinics, in person or via remote consultations

These specialists work alongside psychologists, nurses, haematology teams, and welfare/legal advisors from Southwark Law Centre.

This holistic, person-centred approach rebuilds trust, offers an alternative to hospital-based care, and aligns with the APPG’s call for integrated, community-led solutions.

Enhanced sickle cell community service – MDT clinic

GPs can refer to the sickle cell community nursing teams via the team email address.



> *"The combination of a dietitian and a pharmacist in one session proved to be a game-changer for us. This new way of working is a huge step forward for families like ours. It offers us peace of mind and ensures that our children receive comprehensive, compassionate care."*

- Parent

Peer Mentoring Programme

- Children and young people aged 10 to 24 can benefit from a peer mentoring program run by the Sickle Cell Society.
- **Mentors with lived experience** provide guidance, emotional support and offer practical coping strategies.
- Helps with **managing the condition, moving from child to adult services and getting involved in the community**.
- Specific workshops are planned on welfare advice, neurodiversity and transition
- **Impact**: 120 mentees are on the programme in SE London and 5 mentors.

"My mentor helped me set targets for myself to reduce pain and stress, and to help me improve mentally and physically."

[Sickle Cell Society - Mentee poster](#) [Sickle Cell Society Mentor Information](#)

Community engagement

Community engagement

Let's Talk platform:

- We've created a dedicated page on Let's Talk, SEL ICS's patient engagement platform, specifically for the sickle cell community service.
- A survey was already launched for patients to share their previous experiences with sickle cell services.
- The EQ-5D health related-quality of life survey has been launched

GiST magazine:

- We wrote an article with GSTT in July about sickle cell care at GSTT, and the SEL enhanced sickle cell community service. If you are interested in doing any local/organisational communications like this, we are very happy to support.

Sickle Cell Society X dietitian blog post:

- We partnered with Sickle Cell Society to write up a blog post for our new SEL specialist sickle cell dietitian for sickle cell awareness month.

ITV interview for SCS peer mentoring programme:

- We also secured an ITV interview for the Sickle Cell Society's peer mentoring programme for children and young people, which took place during Sickle Cell Awareness Month in 2024.

NHS
South East London

Enhanced sickle cell community services are coming to South East London

We're launching a new service to offer greater community support for people of all ages with sickle cell disorder in South East London.

Patients will be able to access this service at a number of locations across South East London and will include:

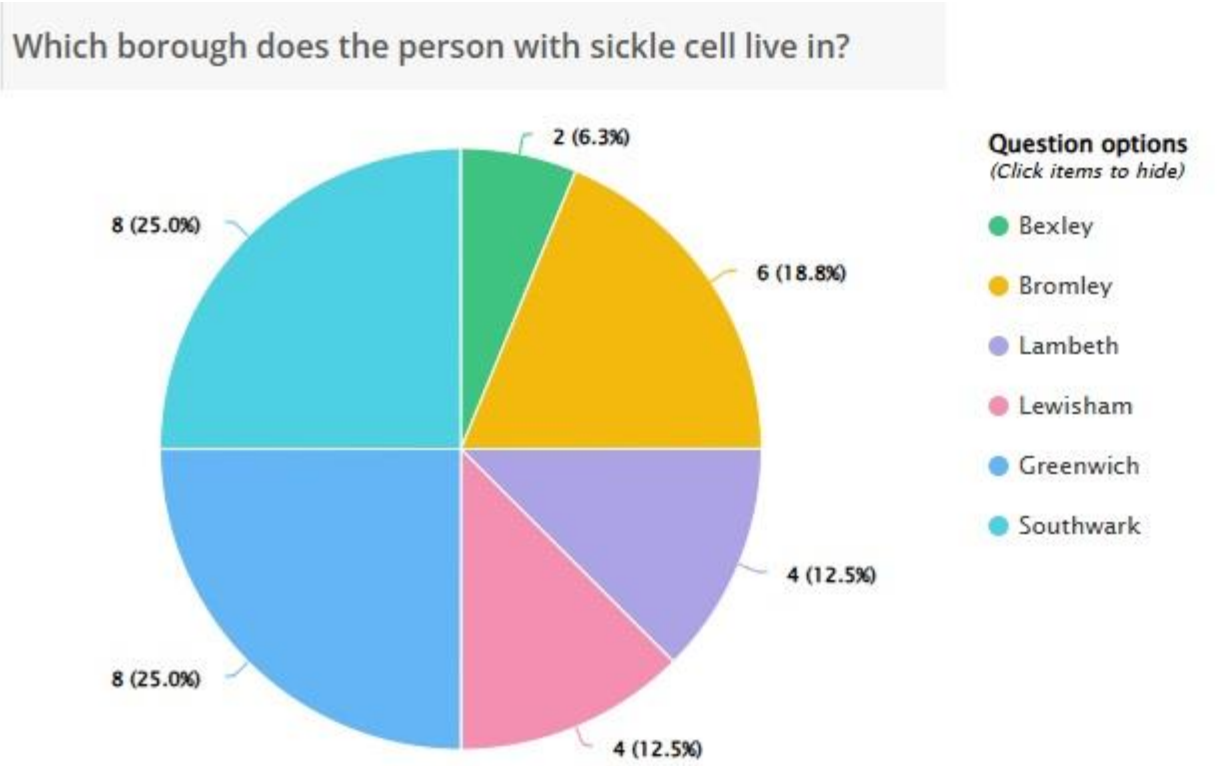
- ☑ More nurses to provide specialist care
- ☑ Team of specialists including dietitians, physiotherapists, psychologists, and pharamcists
- ☑ Help and advice with welfare benefits
- ☑ Peer support for children and young people through the Sickle Cell Society
- ☑ Educational resources for patients, schools, workplaces, and healthcare professionals

To learn more about the service, please visit our website https://bit.ly/SELsicklecellcommunity or email gst-tr.selsicklecommunity@nhs.net.

A collaboration between South East London ICS, South East London and South East HCC, Oxleas NHS Foundation Trust, Bromley Healthcare, Guy's and St Thomas' NHS Foundation Trust, Sickle Cell Society, and Southwark Law Centre.

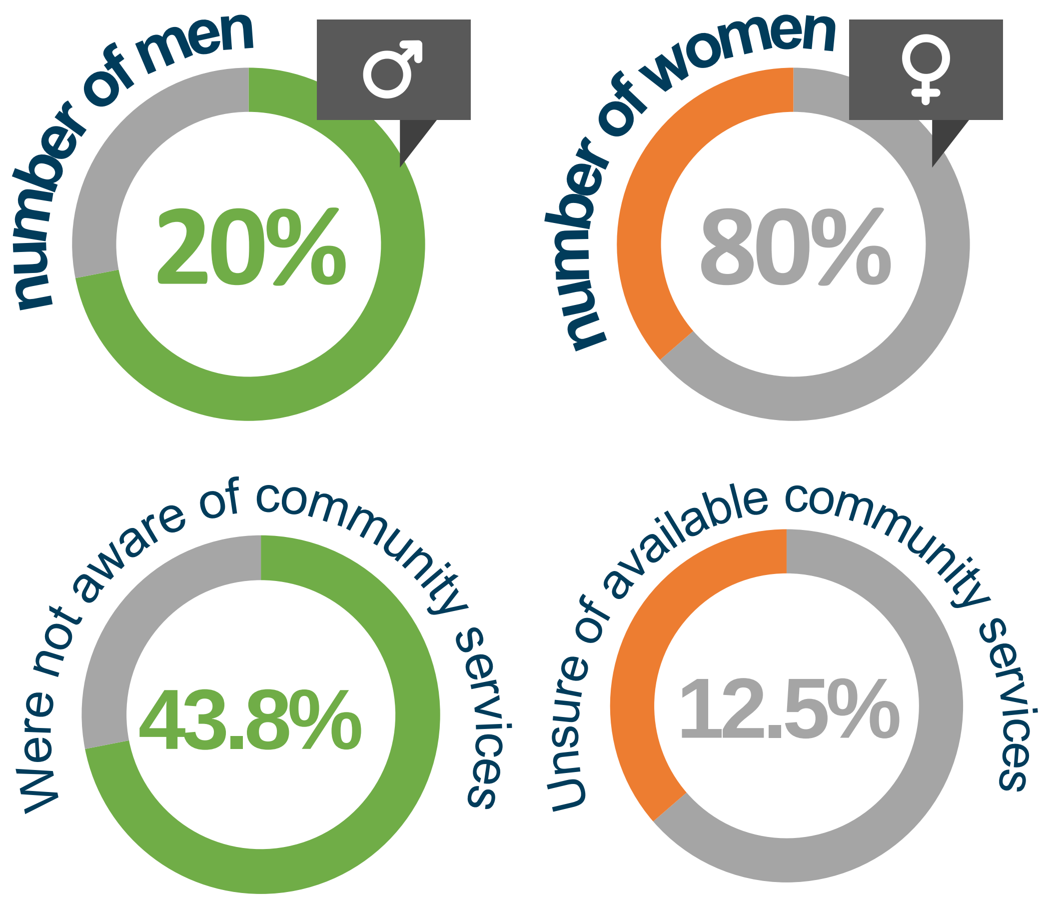
Patient engagement – shaping the enhanced community service survey results

Survey results



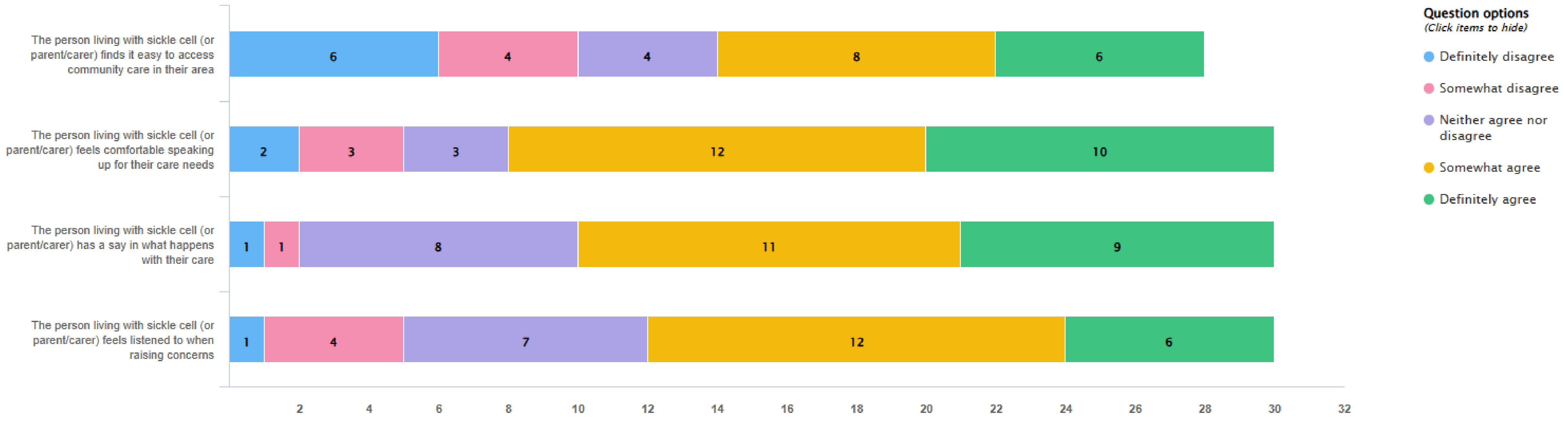
Which borough does the person with sickle cell live in?

Age ranges from 0 – 65+



Survey results

Q10 To what extent do you agree with the following statements



Survey results

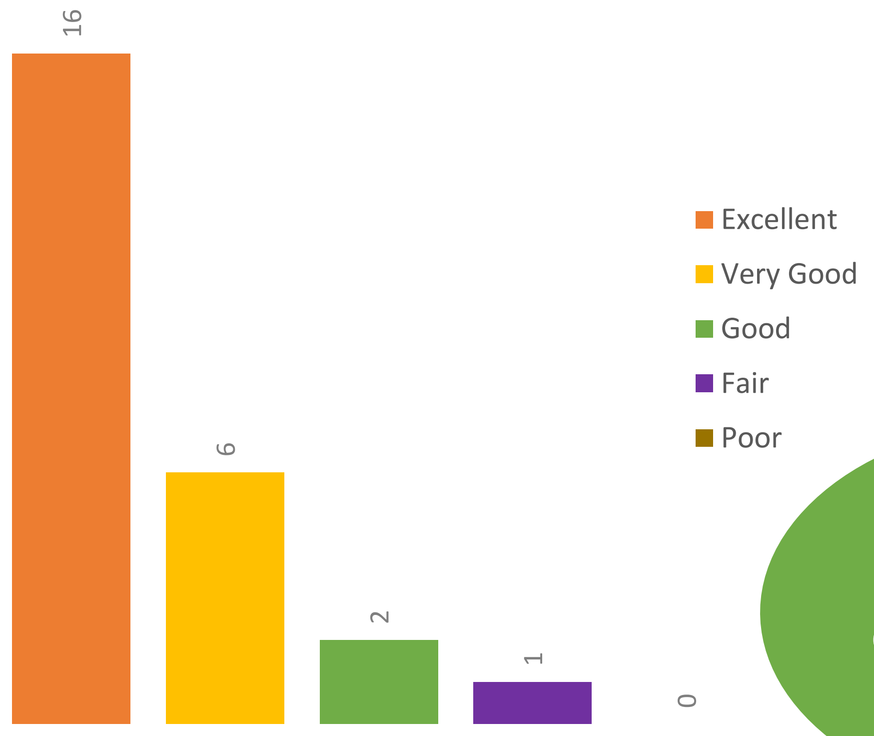
Q: What would the person living with sickle cell (or parent/carer) like to see more or less of in the community for sickle cell care?

South East London
Integrated Care System

The enhanced community service – ongoing feedback

Community engagement – Clinic feedback

Q: What was your overall experience of the clinic, appointment, or group session?



“My son enjoyed the session, fills the form of his daily activities with excitement daily and references what he learnt or was asked to be doing from the session a lot.”

“Good experience because the staff are very kind and caring they walked me feel safe.”

“My welfare officer was exceptional at fighting for the benefits that I was entitled too.”

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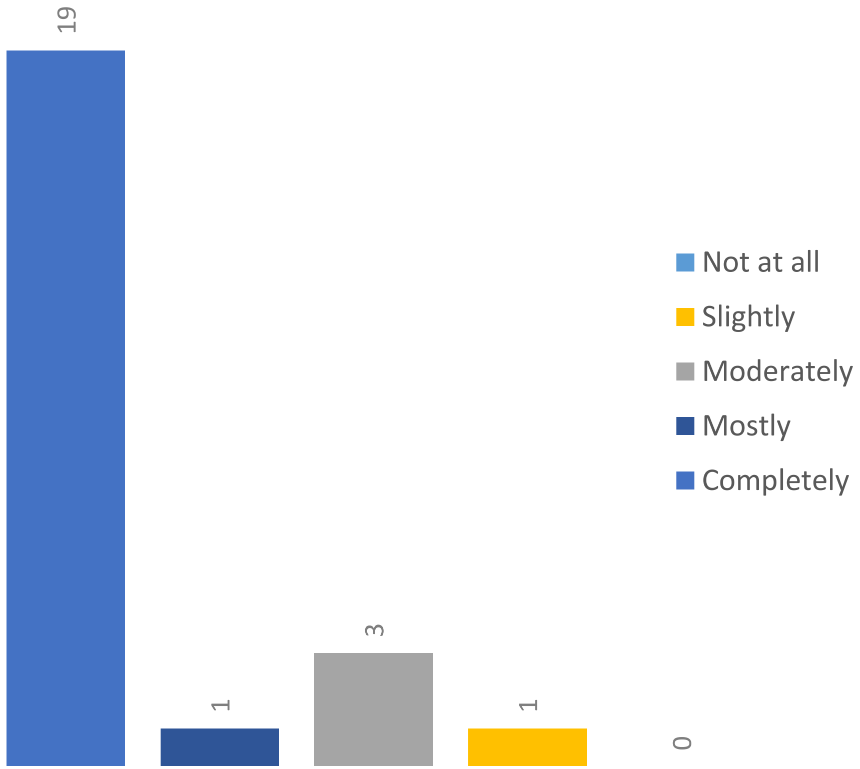
Community engagement – Clinic feedback

Q: To what extent have the healthcare team taken to hear and understand the patient’s perspective, including personal and social needs? For example: housing needs, mental health and wellbeing, caring responsivities



“The dietitian and pharmacist were very engaged with my daughter, which allowed her to feel included and encouraged to speak about her needs. As a parent it was great to speak to both in one session as my questions/concerns bounced between these two areas.”

I felt like the healthcare team took time to listen to my concerns and offer reassurance for support, even on some issues where they seemed unsure they relayed this to me. This was good to hear their honesty and made me feel like I was being taken seriously.

Community engagement – Clinic feedback

Date	You said	We did
March 25	It was encouraging that there has been more funding put into sickle cell but it is important that sickle cell did not become a buzz word. *“the fight to take sickle cell disease seriously has been very traumatic and long fight so I need this new initiative to be effective for all sickle cell warriors”*	We are working with the funding bodies to look at the sustainability of the pilot as well as educational resources to share knowledge of sickle cell across a broad range of services patients will access throughout their lifetime.
March 25	As it was a review session we discussed many things but the core issues were not solved	We are ensuring goals and expectations are discussed during every appointment so we can address what is a priority for you and support long term goals within the community.
Feb 25	The healthcare team seemed a lot more open to listening and understanding your experiences with sickle cell disorder however it seemed that the team had very basic knowledge of sickle cell and how it can affect daily life of someone living with it in all areas, from diet, mental wellbeing, physical health etc. *"It would be good to see an investment in healthcare professionals’ knowledge and understanding of sickle cell so they can provide more tailored care and support."*	We worked on recruiting all posts within the MDT. We have set up monthly training for the community team to build on advance practice which includes opportunities to learn from each other and sickle cell specialist clinicians across south east London. The team also attend any other relevant training and sit in with different clinics in the hospital. Our team advocate sickle cell awareness and education across SEL healthcare services through departmental in-service training, patient forums, staff meetings and community sickle cell events.
April 25	That the information given in group sessions was good but that children did not seem to understand everything about sickle cell and that this is happening in their body. That more educational resources were needed for appropriate ages.	We are looking at creating a resource list based on age range and creating some of our own resources

Next Steps 2025/6

- Continue to shape the enhanced clinic using feedback from patients, parents and carers.
- Evaluate the impact of community model and ED Bypass and opportunities to scale across other SEL hospitals subject to resources.
- Increase GP, workplaces, schools & community health awareness of sickle cell management.
- Develop funding proposals for long-term MDT sustainability.

Questions