

LIVING WITH AND CARING FOR SICKLE CELL SURVEY RESULTS 2023



1

ADULT SURVEY

- 74% doctors and nurses in the clinic knew enough about sickle cell
- 87% doctors and nurses talked in a way you could understand
- Only 37% doctors and nurses in ED knew enough about SCD
- Only 36% felt that emergency staff helped ease pain
- 49% were not offered psychology support



2

PARENT SURVEY

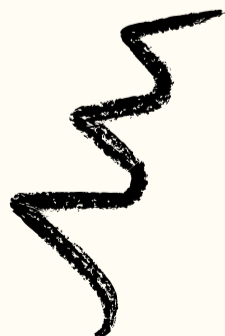
- 77% doctors and nurses in the clinic knew enough about sickle cell
- 92% doctors and nurses talked in a way you could understand
- 70% doctors and nurses in ED knew enough about SCD
- 59% felt that emergency staff helped ease pain
- 59% did not see a psychologist or counsellor
- 78% had enough information about coping with pain



3

CHILD SURVEY

- 79% doctors and nurses knew enough about sickle cell
- 76% Felt friends did not know enough about sickle cell
- 42% did not get chance to meet others with sickle cell
- 93% felt they were given sufficient help to cope with SCD



WHAT YOU SAID- LIVING WITH AND CARING FOR SICKLE CELL SURVEY RESULTS 2023

THINGS THAT NEED TO IMPROVE

1

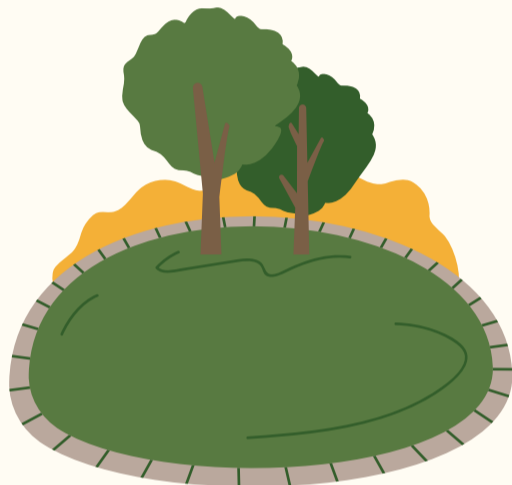
- Improved care in A&E, including better training and empathy from staff
- More information about the disease and treatment options, including alternative medicine
- More opportunities to connect with others in similar situations
- More efficient appointment scheduling
- More advocacy for SCD patients, including access to financial assistance and social services



THINGS THAT ARE GOING WELL

2

- Specialist nurses and doctors actively listening, understanding, and empathising with patients' perspectives and concerns
- Ease of access to care in specialised hospitals, including referrals, emergency treatment, and consultations



WHAT NEXT?

3

- We will ensure your suggestions for improvement are heard
- We will work with our emergency teams to ensure timely access to pain management
- We have designed mandatory training modules for A&E staff looking after sickle cell patients



This survey was done in 2023 in the following South East London Specialist Sickle Cell Hospitals:

King's College Hospital
Guy's and St Thomas's Hospital
Croydon university Hospital
Lewisham Hospital
Queen Elizabeth Hospital Woolwich