picker Institute Europe

SICKLE CELL SOCIETY

Living with Sickle Cell Disease

Sickle cell disease is often invisible in nature: **people look well despite experiencing regular episodes of excruciating pain.** It is important to understand their experiences of living with the condition to identify how we can improve their care.

A survey of patients with sickle cell disease and their families revealed that **greater awareness of the condition**, and **more information about coping with pain and treatment options**, would improve their experiences.

The survey also revealed **poorer understanding and knowledge** of the condition from staff in emergency care settings compared to specialist-led healthcare staff.

Knowledge of healthcare staff

Healthcare staff definitely knew **enough about sickle cell disease:**

in specialist planned care settings.

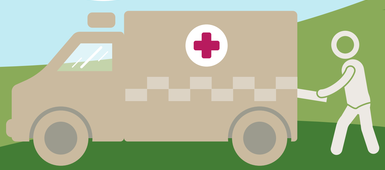
in emergency care settings.

Understanding from healthcare staff

Healthcare staff were **fully sympathetic and understanding**:

in specialist planned care settings.

in emergency care settings.



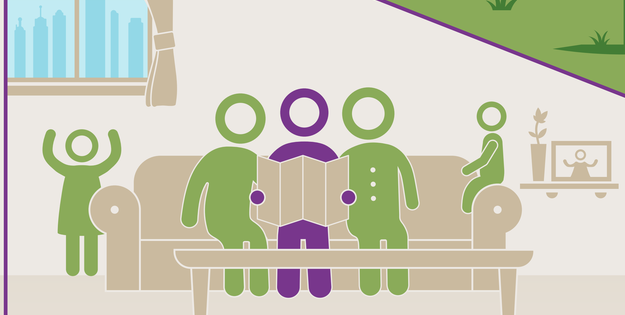
Understanding from friends, family & society

of respondents felt their friends, family and co-workers **did not know or understand enough about their condition.**

reported healthcare staff **did not give enough information to others,** such as schools or employers, about their condition.

Coping with pain

of respondents felt they did not have enough information about **coping with pain.**



Treatment options

of respondents did not have enough information about **different treatment options** but would like this.

*Quote obtained from a focus group of adults with sickle cell disease conducted in 2014.

The data was gathered from a survey administered between March and October 2015 from a total of 722 respondents: 280 adults aged 16+ with Sickle Cell Disease (SCD); 220 parents of children aged 0-15 with SCD; 222 children aged 8-15 with SCD.

This research was funded by the NIHR CLAHRC Northwest London. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

Funded & supported by NHS National Institute for Health Research