

SICKLE CELL DISEASE

SICKLE CELL DISEASE (SCD) IS THE UK'S BIGGEST GENETIC BLOOD DISORDER.

SCD 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 BY PICKER AND NIHR CLAHRC NORTHWEST LONDON IN PARTNERSHIP WITH THE SICKLE CELL SOCIETY, FOUND THE NEED FOR GREATER AWARENESS OF THE CONDITION AND MORE INFORMATION ABOUT COPING WITH PAIN AND TREATMENT OPTIONS.



NIHR CLAHRC East Midlands
Collaboration for Leadership in
Applied Health Research and Care

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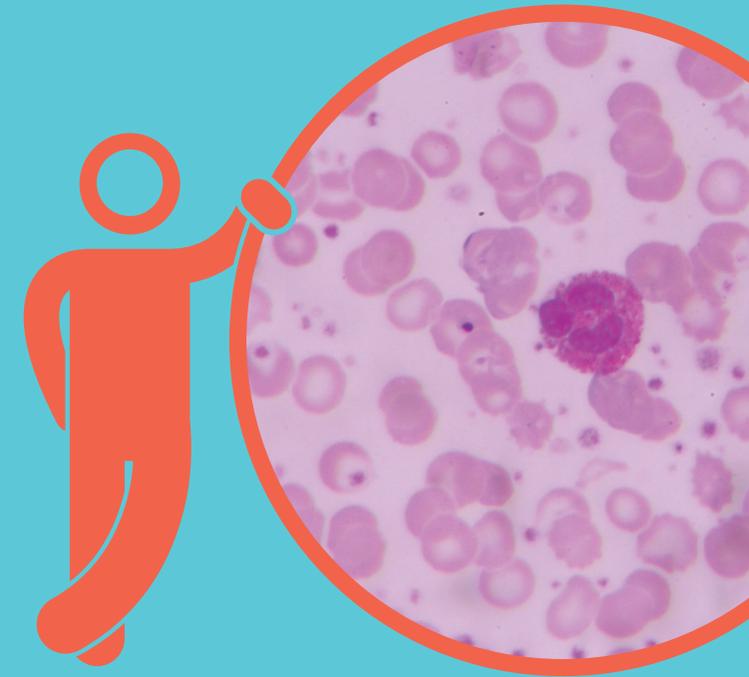
National Institute for
Health Research

This document is funded by the National Institute for Health Research's Collaboration for Leadership in Applied Health Research and Care East Midlands.

The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

For further information on sickle cell disease visit:

www.sicklecellsociety.org

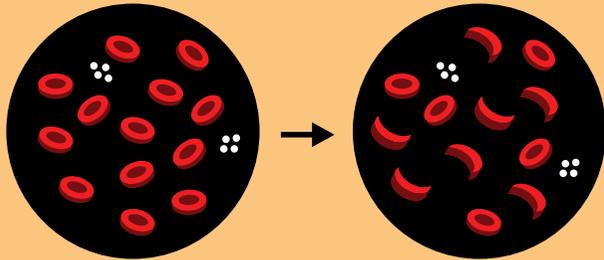


AWARENESS OF SICKLE CELL DISEASE

A survey by Picker and NIHR CLAHRC Northwest London in partnership with the Sickle Cell Society

HOW IS SCD CAUSED?

SCD produces unusually shaped rigid red blood cells that can cause problems as they can become stuck in blood vessels.



NORMAL

SCD

HOW MANY PEOPLE HAVE SCD?

SCD affects approximately 15,000 people in England.



KNOWLEDGE OF HEALTHCARE STAFF



Healthcare staff 'Definitely knew enough about SCD':

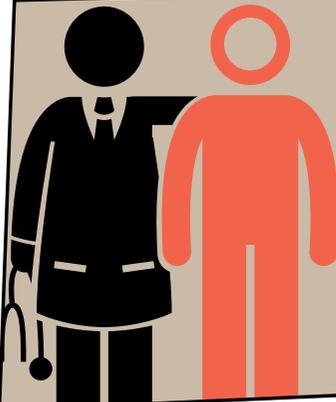
- 76% in specialist planned care settings
- 45% in emergency care settings

COPING WITH PAIN

38% of respondents felt they did not have enough information about coping with pain



UNDERSTANDING FROM HEALTHCARE STAFF



Healthcare staff were fully sympathetic and understanding:

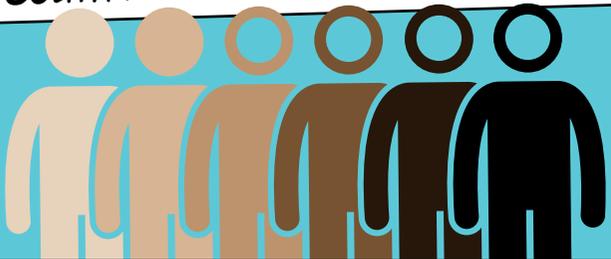
- 68% in specialist planned care settings.
- 51% in emergency care settings

UNDERSTANDING FROM FRIENDS, FAMILY & SOCIETY



- 86% of respondents felt their friends, family and co-workers did not know or understand enough about their condition.
- 62% reported healthcare staff did not give enough information to others, such as schools or employers, about their condition.

SCD IS MORE COMMON IN INDIVIDUALS WITH AN AFRICAN OR CARIBBEAN AND SOUTH ASIAN FAMILY BACKGROUNDS



TREATMENT OPTIONS



21% of respondents did not have enough information about different treatment options but would like this.

LIVING WITH SCD

"When people look at you they think there's nothing wrong, because it's not visible in any way".

