

# People with sickle cell disease as active participants in a project to improve the primary care experience in northwest London

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## 1. Aims

The aim of the project is to improve the quality of care patients with Sickle Cell Disease receive from their GP by:

- Improving GPs knowledge about Sickle
- Raising awareness of new UK standards of care
- Engaging and empowering patients with Sickle

## 2. Background

Sickle Cell Disease (SCD) is the most common and fastest growing genetic blood disorder in England, predominantly affecting Black and ethnic minority (BME) groups. "Sickle" is one of the most common reason to be admitted to hospital for this patient group and is likely to result in repeat admissions.

## 3. Problem

A national enquiry into patient outcomes and deaths in 2008 identified the role of GPs in increasing vaccination and antibiotic use to prevent complications as essential. The report recommended that improving the care patients receive from their GP could result in less patients seeking help from local accident and emergency departments.

## 4. Research

This study involved patients, carers and staff from the Sickle Cell Society along with doctors and nurses from a hospital, GPs, public health staff from the Primary Care Trust and researchers from the NHS and university. In order to better understand that concerns of patients about why they didn't see their GP a focus group and survey was undertaken. These identified a number of issues for patients including:

- Access to urgent appointments
- Poor communication between health professionals
- No proactive role in maintaining health
- Limited knowledge about Sickle Cell Disease and the standards of care

Understanding these issues from a patients perspective led to the development of training and materials to support GPs to better care for their patients with Sickle.



## 5. Effects of change

The project team have provided training and materials to support GPs in 13 surgeries in Brent. Work is underway to establish the effectiveness of the training and support in improving care for patients with Sickle.

"I've really appreciated the support from CLAHRC to continually develop...once you've been involved you're in for life" Patrick Ojeer

## 6. Patrick and Comforts' View

Patrick and Comfort are members of the Sickle Cell Society and helped initiate and drive the project. These are their thoughts on challenges and benefits to being involved and lessons for others.

### Challenges

- Simple changes can have a huge impact and it can be frustrating that these changes don't happen
- There is still so much to be done and so many people that need help

### Benefits

- Getting involved in the project can really expand your networks and help you develop new skills, especially when there are people to support you.
- Developing the confidence that you can change the system

### Lessons for others

- Appreciate that patients understand the system as well as healthcare professionals- just a different kind of understanding
- Involve service users whenever you can- provide an opportunity and there will be no shortage of people who want to get involved

**Acknowledgements:** We thank all our colleagues across many organisations in northwest London that form part of the Sickle Cell Steering Committee for their dedication to a project that focuses on improving patient quality of care at the primary care level for an under served population.