

The Heritage Project: Our Story, Our journey



Our Journey Our Story

Share your Sickle Cell Story

photo credit: June Okochi

The **Sickle Cell Society** is presenting a new project in 2020 exploring the history of Sickle Cell in the UK since the Windrush generation's arrival. Help us shine the light on the **UK's fastest growing genetic condition**. Sickle Cell predominantly affects people from **Black African and Caribbean heritage**. Whether you are patient, a carer, a family member of a sickle cell patient, a campaigner or medical professional, **share your story** by contacting alinta.sara@sicklecellsociety.org



We are inviting you to take part in our heritage project: *Our story, our journey*, a programme of work supported by the Heritage Lottery Fund (HLF), which will chart a history of sickle cell disorders (SCD) in the UK since the Windrush generation's arrival. SCD predominantly affects people of Black African and Caribbean heritage and is now the UK's fastest-growing genetic condition – changes over the last 70 years have been immense. This project is necessary and crucial. Although SCD has been medically recognised as a health condition for over a century, awareness of it remains relatively low and people with SCD are still facing stigma.

A key part of the project is to record oral histories that will be preserved and make publicly accessible the stories and memorabilia contributed by participants. Before you decide, it is important for you to understand why the work is being undertaken and what it will involve. Please take the time to read the following information. Take time to decide whether you wish to take part.

Who will conduct the research?

The research will be conducted by Alinta Sara, Heritage project lead at the Sickle Cell Society and her team as well as Grace Redhead (project consultant)

What is the purpose of the research?

The research project will look at:

The issues faced by people with SCD (and carriers of the trait) and their families
How campaigning and lobbying has dramatically increased awareness and understanding of SCD, improved standards of care, increased diagnosis and informed research and treatment

The role of the NHS, patient support groups and the Sickle Cell Society
Recognising the individuals to whom we owe thanks for their tireless hard work and commitment to the cause.

The project will target participant groups in London and the Midlands (where SCD prevalence is high), engaging a much wider audience in public events.

What would I be asked to do if I took part?

If you decided to take part, you will be invited to take part in an interview, which will last between 1 and 2 hours, and be either audio or video recorded. The interview is an opportunity to share your stories. The interview is very flexible and you are free to discuss what seems to you to be the most important.

With your permission, your recorded interview will be safely held by the Sickle Cell Society with the intent to preserve in public archives for permanent use in research, publications, education, lectures, broadcasting, and the internet. The interviewer may also ask you to take your photograph. If you agree, the photograph will also be part of the archives where it will be preserved as a permanent resource for use in research, publications, education, lectures, broadcasting, and the internet.



What happens to the data collected?

A key part of the project is the recording of oral histories that will preserve and make publicly accessible the stories and memorabilia contributed by participants. With your permission, your recorded interview will become part of the digital archives but will also be used as part of a film and an exhibition. It will also be preserved as a permanent resource for use in research, publications, education, lectures, broadcasting, and the internet. We will never use your information without your consent, and you can tell us how it should be used on the Heritage Project Recording agreement, which you will complete after your interview.

You have the following options:

- Use my name: you can tell us to credit you by name when we use your contributions on the website, in print, and public.
- Use a pseudonym: You can choose to use a pseudonym. The pseudonym will be the name used in the archives and the name attributed to your contributions on the website, in print, and public.

Occasionally you may wish to request partial or complete closure of your interview to public access.



**SICKLE
CELL
SOCIETY**