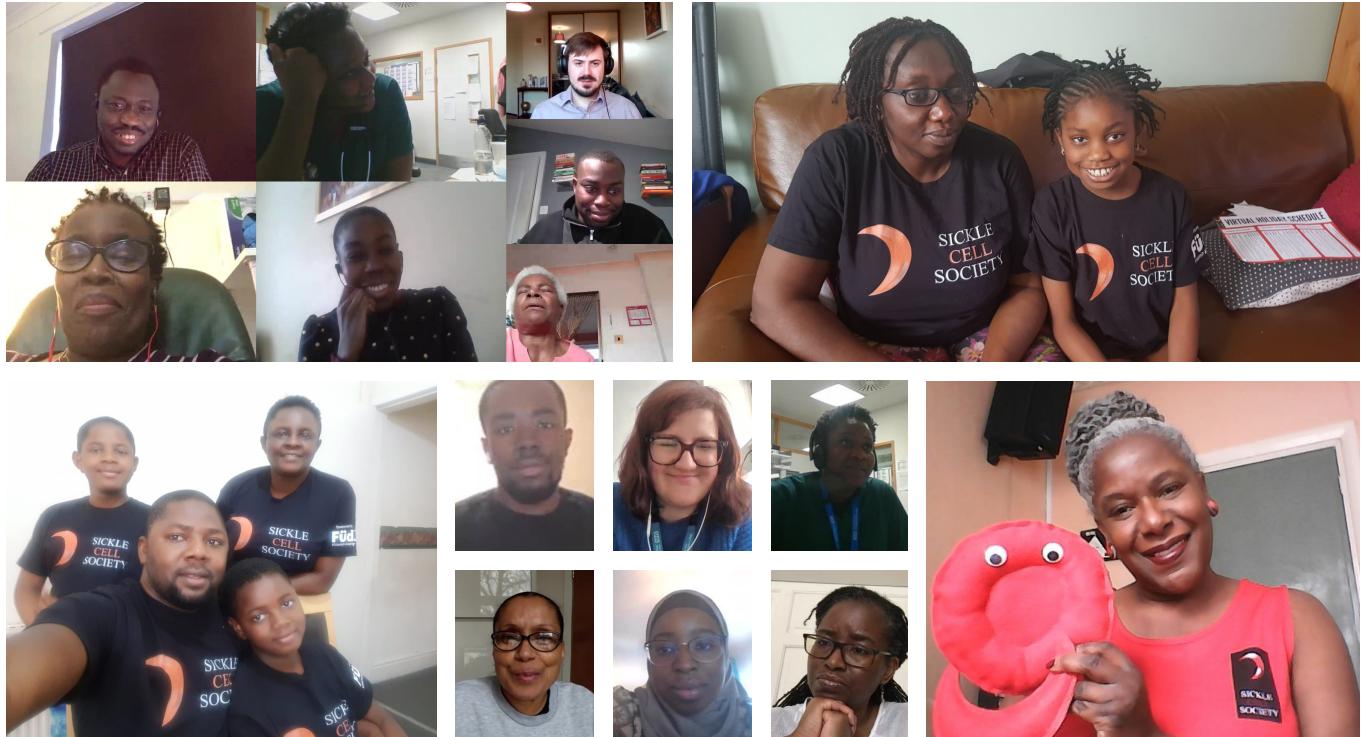




2020/21 IMPACT REPORT



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Summary Statement

This year has been a thoroughly difficult and challenging year for everyone in the UK and across the world and we know that the sickle cell community has been deeply affected. Despite seeing a big impact on our finances and having to work remotely, we have worked hard as an organization to continue supporting the sickle cell community as best as we can, including ensuring that sickle cell was included in the shielding category and working with sickle cell experts to ensure up-to-date advice and information was available.

The annual report is an opportunity for us to showcase the ways in which we continue to support people living with sickle cell at a local and national level. Over the last year, we have continued to experience global uncertainty and turbulence leading to funding constraints and an increased workload.

However, we have continued to work hard to meet the high standards of the sickle cell community and we hope that this report will show you the range of work we have been doing to continue to see visible improvements and impact for people living with sickle cell and their families. A few of these highlights include:



- Developing up-to-date and sickle cell specific advice and guidance on coronavirus and the vaccine including on our website and a series of Live Q&As and vaccine information videos.
- **Launched the Our Journey Our Story exhibition digitally on the Black Cultural Archives website**
- Published Cast Aside and Forgotten an All-Party Parliamentary Group for Sickle Cell and Thalassaemia report into the impact of the COVID-19 pandemic on the sickle cell community.
- Published '**A Parent's Guide to Managing Sickle Cell Disease' (4th Edition 2021)** and '**Sickle Cell & Thalassaemia Counselling, Knowledge & Skills Guidelines' (2020)**.
- Joined a nation-wide charity collaboration to write an open letter to encourage those with underlying health conditions to come forward for the coronavirus vaccine
- **Continuing working with the Sickle Cell World Assessment Survey (one of world's largest sickle cell surveys published in 2019) to share and educate on the survey's findings.**
- Writing a letter to Boris Johnson to urge the Prime Minister to not lose smaller charity partnerships like the Sickle Cell Society in the Public Health England restructure.
- **Celebrated key awareness days like World Sickle Cell Day and Rare Disease Day by hosting and participating in a range of events and awareness campaigns.**
- We saw the growth of our blood donation project, building on the success of two years raising awareness of blood donation and recruiting black-heritage blood donors under our 'South London Gives' project we were able to continue this work nationally via Give Blood, Spread Love, England.

- Continuing to work with pharmaceutical companies on clinical trials for potentially new sickle cell modifying drugs
- Continued our children's activities (virtually) with funding from Global's Make Some Noise
- Ran a successful Children's Holiday virtually, engaging children and their families.

With the vaccine roll-out we are hopeful that life will be able to move to a new normal although we know that there will continue to be significant turbulence and challenges for the Society and the wider sickle cell community.

Despite these challenges, we remain committed to supporting the sickle cell community, our staff and volunteers. We will continue the positive work we have done this year, doing so with good governance, transparency, and accountability. We want to say a massive thank you to all our staff and volunteers for their unwavering commitment during this challenging period and a thank you to all of our members, donors, and other supporters, for their continued love and support.

Although the news surrounding the death of Richard Okorogheye and the inquest into the death of Evan Nathan Smith came after the dates of this Impact Report, we want to make mention of it now to reassure the community that we are working hard to see national change. You can find a full statement at our website.

We hope you enjoy reading this report of all we have been up to over 2020/21 and that it will provide you with an insight into our work.

Kye Gbangbola
Chair

John James OBE
Chief Executive





The Sickle Cell Society exists to assist and empower people with sickle cell disorder to achieve their full economic and social potential.

We provide recreational activities for affected individuals and their families.

We work towards the improvement of public information, assisting in research into the causes, treatment of the condition and dissemination of such information.



Membership

The Sickle Cell Society has maintained its free membership policy and the current membership stands at almost 2000. Whilst our membership numbers continue to grow, we are no longer including our wide range of additional supporters, groups and stakeholders, who continue to support our work, in this figure.

Around
2,000
Members

Members receive two print or PDF newsletters a year as well as a monthly e-newsletter and other emails about projects and events.

The Sickle Cell Society is the national umbrella for over 40 independent support groups, voluntary organisations and statutory centres across the UK.

We are always looking for new members to join the Society, inviting people to join through our website, social media, and at events and talks.

Become a member here: www.sicklecellsociety.org/membership/



Media and Communication

-  Our Twitter page has gained over 800 new followers
-  Our Facebook page has gained almost 500 new followers
-  Our Instagram account has gained over 1800 followers
-  Our LinkedIn account has gained almost 400 followers

The Sickle Cell Society website receives, on average, 33,000 views per month (up 37.5% from last year).

On average, 8500, of those views per month were specifically views for our Coronavirus (COVID-19) & Sickle Cell Disorder page

33,000
Average
views per
month

Hackney & City Mentoring Scheme

The Mentoring Scheme remains on pause whilst we continue conversations with Hackney Clinical Commissioning Group as well as the other East London Clinical Commissioning Groups (CCGs) across the seven boroughs. The conversations are about the potential expansion of the Mentoring Scheme, which we have successfully piloted over two years.

Discussions have also begun about the potential roll out of the Peer Mentoring Scheme with both Commissioners in Greater Manchester and the Sickle Cell Health Coordinating Centre for the North West of England.

Helpline and Information

The Society received 224 telephone calls from April 2020 to March 2021.

The Society provided information and support for 99.9% of all calls – with 83% receiving information, support or being signposted to relevant places.

The most common topics of calls were COVID-19 related, managing sickle cell, benefits, fundraising and awareness.

82% of callers were new callers. The team spent a total of 3411 minutes (approx. 57 hours) on the phone.

**3411
Minutes
spent on the
phone**

**86%
of all emails
received
information,
support and
advice.**

As part of the helpline service we also responded to emails. The Society received a total of 1004 emails during April 2020 to March 2021.

86% of emails received information, support and advice. 11% of emails were signposted to relevant places.

Coronavirus (COVID-19)

Coronavirus (COVID-19) has had a huge impact on the sickle cell community. We created a dedicated page on our website to provide the latest information and guidance, specific to sickle cell and COVID-19). As well as detailing national guidelines, the website contained up-to-date data from the National Haemoglobinopathy Panel (NHP), and guidance developed by our medical advisors.

8500
average
views per
month

Further to our website, we hosted and created a range of online resources including:

3 **Coronavirus and Sickle Cell Live Q&As**

With panelists including:

- **John James OBE** (CEO, Sickle Cell Society)
- **June Okochi** (Head Of Program Management, NHS West Essex CCG, and Lead Mentor, SCS Mentoring Programme)
- **Professor David Rees** (Consultant Paediatric Haematologist and SCS Medical Adviser)
- **Dr Kofi Anie** (Consultant Psychologist and SCS Medical Adviser)
- **Dr Mark Layton** (Consultant Haematologist and SCS Medical Adviser)

3 Vaccine Information Videos

The series included information on how the vaccine was developed with Dr Anna Goodman, a presentation on the sickle cell and COVID-19 data with Dr Rachel Kesse-Adu and a Q&A with sickle cell patients who have had the vaccine.

You can find all of our Coronavirus (COVID-19) and Sickle Cell information, including all of the videos, guidelines and data at our website: www.sicklecellsociety.org/coronavirus-and-scd/





Hackney Engagement Project

The Hackney Engagement Project looked at how to continue its work in a virtual capacity in order to adapt to the coronavirus pandemic. The project utilized the expertise of the sickle cell community and produced a range of videos focused on physical, mental and emotional health, which included:

- Sickle cell workouts as part of #MondayMotivation
- Healthy eating in partnership with Kiddy Cook SE London.
- Open discussions 'panels' led by people living with sickle cell or parenting children with sickle cell.

We are in discussions with Hackney Council about the future of the project.

Education & Awareness

The Society continued to be the leading public source for information on sickle cell at national and international levels by providing information, advice and referral service in response to thousands of letters, email requests and telephone calls.

Staff, Trustees and Volunteers continued to provide awareness talks and presentations within local and national businesses, schools, universities, churches, government and corporate organisations in order to raise awareness of sickle cell disorder and the important work of the Society. The majority of these have been done virtually, to adhere to government guidelines.

The Society continued to engage with various press and media, facilitating patients, staff and other stakeholders to take part in interviews, news features and other media discussions.

The Society ran a range of education events specifically about Coronavirus (COVID-19) & Sickle Cell Disorder.



**10 Facts about
Sickle Cell Disorder**



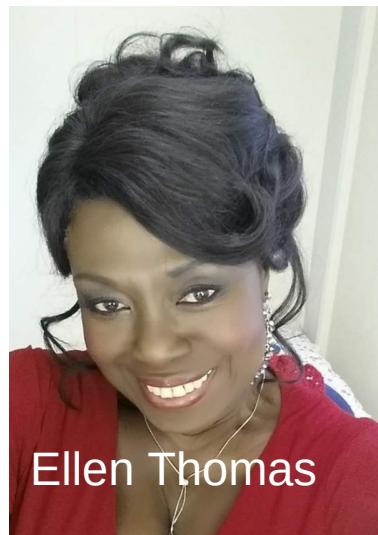
World Sickle Cell Day

The Society continues to honour the United Nations declaration of World Sickle Cell Day on 19th June each year by celebrating the day and raising awareness of sickle cell disorder through various initiatives within the local community. This year we did this with awareness and education video and graphics published on our social media channels as well as making them available for others to use and share.

We also participated and promoted '**Wear Red for Sickle Cell**' an awareness initiative to get as many people as possible wearing red and starting conversation around sickle cell. We have participants from across the country, including our patron and actress Ellen Thomas, as well as around the world in places such as the USA and Sierra Leone.

We also ran and took part in a range of events on and around World Sickle Cell Day. These included:

- Sickle Cell Disorders and the Call for Black Blood Donors
- Sickle Cell Disease and its West African Discovery
- Current Advocacy Work in Sickle Cell Disease: The Global Perspective (GASCDO)



Parliamentary Work

The All-Party Parliamentary Group on Sickle Cell and Thalassaemia (SCTAPPG) aims to be the voice in Parliament of Sickle Cell and Thalassaemia patients and their families.

COVID-19 Research - National Haemoglobinopathy Panel

Hosted a meeting on a National study of Haemoglobinopathies and COVID-19 and the impact on the sickle cell community

Publications

"Cast Aside and Forgotten" The SCTAPPG report into the experiences of those living with sickle cell or caring for someone with sickle cell during the COVID-19 pandemic

Key Collaborations

- Acting as a consultee on Betibeglogene autotemcel for treating transfusion- dependent beta-thalassaemia
- Stem Cell Transplantation APPG
- Vulnerable Groups to Pandemics APPG
- The Specialised Healthcare Alliance
- Nursing and Midwifery Education Steering Group
- Infected Blood Inquiry
- The House of Lords COVID-19 Committee
- Coordinated Parliamentary activity on improving access to treatments for rare diseases with MACPharma
- Submitted evidence to the joint inquiry on 'lessons to be learned' from the pandemic response.



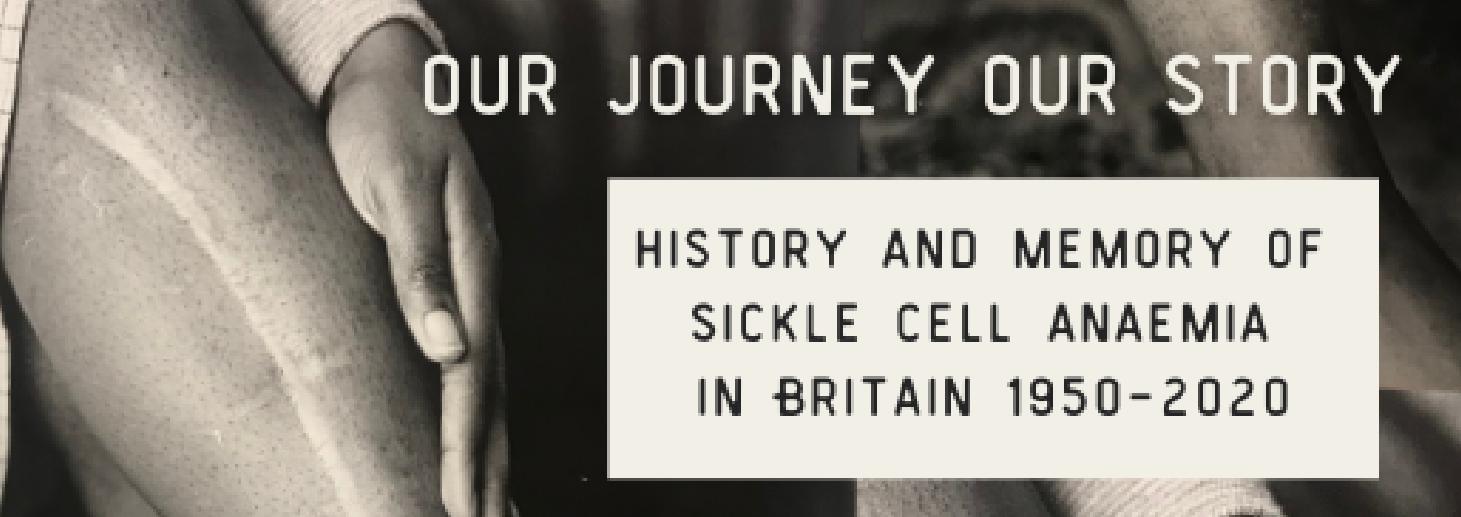
Our Journey, Our Story

Our Journey, Our Story collected oral history as part of the Sickle Cell Society's Heritage Project funded by the Heritage Lottery Fund. The project charts a history of sickle cell disorders (SCD) in the UK since the Windrush generation's arrival.

This project looked at the issues faced by people with SCD (and carriers of the trait) and their families, the role of the NHS, patient support groups and the Sickle Cell Society, how campaigning and lobbying has dramatically increased awareness and understanding of SCD.

Key Achievements

- Researched SCD heritage through gathering 22 boxes of archival materials from sources including Tate Britain, Black Cultural Archives, SCS archives and De Montfort University
- Collected 32 oral history interviews
- Delivered 4 workshops and engaged with young people through 4 filmmaking masterclasses
- Launched the exhibition online
- Ran 2 public webinars to over 50 people
- A live event with Professor Dame Elizabeth Anionwu and BCA director Arike Oke.



OUR JOURNEY OUR STORY

**HISTORY AND MEMORY OF
SICKLE CELL ANAEMIA
IN BRITAIN 1950-2020**

The Screening Programme

From 1 April 2020 – 31 March 2021 the Sickle Cell Society (SCS) and UK Thalassaemia Society (UKTS) continued working on the collaborative project with the NHS Sickle Cell and Thalassaemia Screening Programme (NHS SCT Screening Programme) which officially commenced on 15 August 2018.

The unprecedented COVID-19 pandemic of 2020 affected delivery of some project objectives and caused changes in the work plan previously proposed. We found new ways of working and adapted our workplan to continue to prioritise antenatal and new-born screening in England as safely as possible.

All of the year's planned outreach and face-to-face work was affected and all meetings were done online, in addition, a new work stream was prioritised.

Key Project Achievements

- Major input in the revision of the NHS SCT Screening Programme E-learning resource to support health professionals who are part of the screening pathway.
- Review of NHS SCT Screening Programme antenatal and newborn carrier leaflets.
- Publications of Paediatric Standards and Parents' Handbook on the Management of Sickle Cell.

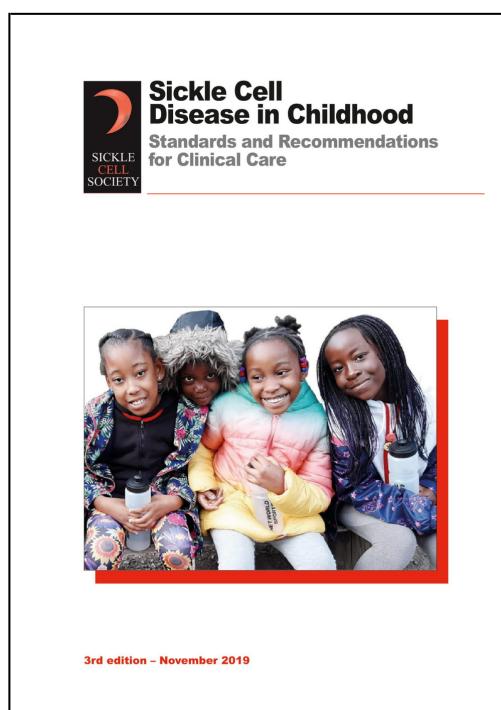
"Thanks Iyamide. Overseas programs are drawing on UK best practice, it's important to say we use the Public Health England Sickle Cell and Thalassaemia leaflets EVERY DAY".

Quote from attendee at Publications launch

The Screening Programme

Key Project Achievements (continued)

- Collaboration with NHSSCT Screening Programme and UKTS to launch 'Sickle Cell Disease in Childhood: Standards and Guidelines for Clinical Care', 'Parents' Guide to Managing Sickle Cell Disease' and 'Sickle Cell & Thalassaemia Counselling, Knowledge & Skills Guidelines' attended by over 250 people. (Download at our website: www.sicklecellsociety.org/publicationlaunch/)
- Raised awareness through: online talks (7) newsletter article (1), Webinars/Conferences (5), Radio Interview (1) Newspaper articles (3) PHE Blog (1)
- Outreach using specially designed social media screening graphics for WSCD, July SCD Awareness Month and Rare Disease Day.
- Raised awareness of screening as part of virtual advent calendar of Dawn Butler MP



Children's Holiday

32 Families from all around the country joined us online

From 14th-16th August we hosted our first ever Virtual Children's Holiday. We have been running our Annual Children's Holiday for 8-15 year olds with sickle cell every year since the 1980s but this year, to keep everyone safe, we took our normal adventures online for the very first time!

We got up to a whole range of activities put together by our Children's Activities Team. These included:

- Storytelling
- Tai Chi
- Yoga and Meditation
- Arts and Crafts
- Cabin Chat
- Challenge Night
- Growing Cress
- A Scavenger Hunt
- Sickle Cell Information Sessions
- Parent to Parent Chats

"I enjoyed meeting people who have sickle cell. It's nice to have friends who understand ... if I have pain they know what I'm going through" - Young Person



Children's Activities

The children have taken part in numerous activities virtually from July 2020-May 2021, these included:

- Carnival Themed Workshop
- Black History Month events
- A festival performance
- Positive Wellbeing Workshop
- Cooking Workshop
- T-shirt Design Workshop
- Arts and Crafts
- Meditation Workshop
- Confidence building
- Family Comedy Show

Although our activities have taken place online the children still enjoyed and got the most out of it from home.

We have also started running Monthly Parent Talks, giving parents who have children with sickle cell, a chance to express any concerns/worries or share any advice. The parents have found them very beneficial.

Positive feedback that we've received:

"Thank you for this. It's really nice of the SCS for doing all these session in coronavirus lockdown"

"You are doing very well and helping children with sickle cell thank you so much"

"Thoroughly enjoyed this workshop again. Thanks to the organisers. God bless you for your time and input."

"Keep the discussions coming it is so helpful. Thank you"



South London Gives

During 2020/2021, South London Gives (SLG) delivered the second year of a pilot project focused on blood donation awareness among people of black heritage in England.

The project aimed to test the effectiveness of a formulised Community Organising approach in encouraging more black heritage people to engage with the subject of blood donation and become blood donors.

48

Awareness raising and recruitment activities

Community Advocate volunteers recruited

21

650

New people recruited to the blood donation register

Give Blood Spread Love

Recognising the urgent need for blood donors from black and mixed-race communities in London and Birmingham, Give Blood, Spread Love uses new media to build awareness, share facts, breakdown myths and direct people to sign up to the blood donation register, and go a step further by asking peers to do the same.

46

**Members of the Give Blood Squad
(support network of individuals)**

**Digital resources developed and
shared online**

114

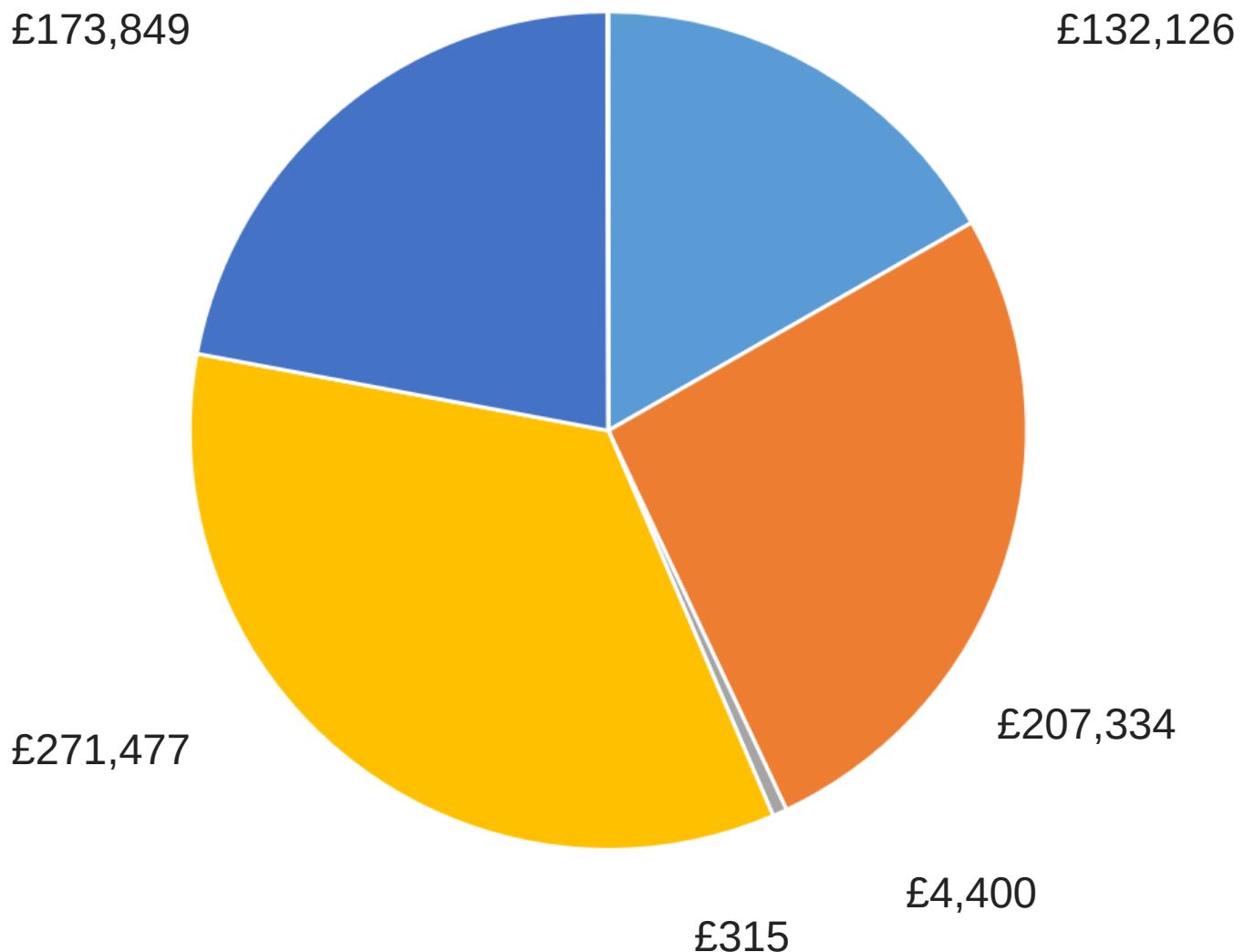
**76,423
Impressions**

**The direct number of users
who have seen GBSL content**



Financial Summary

Total Income: £789,501



Restricted Grants



Unrestricted Donation



Contracts



Unrestricted Grants



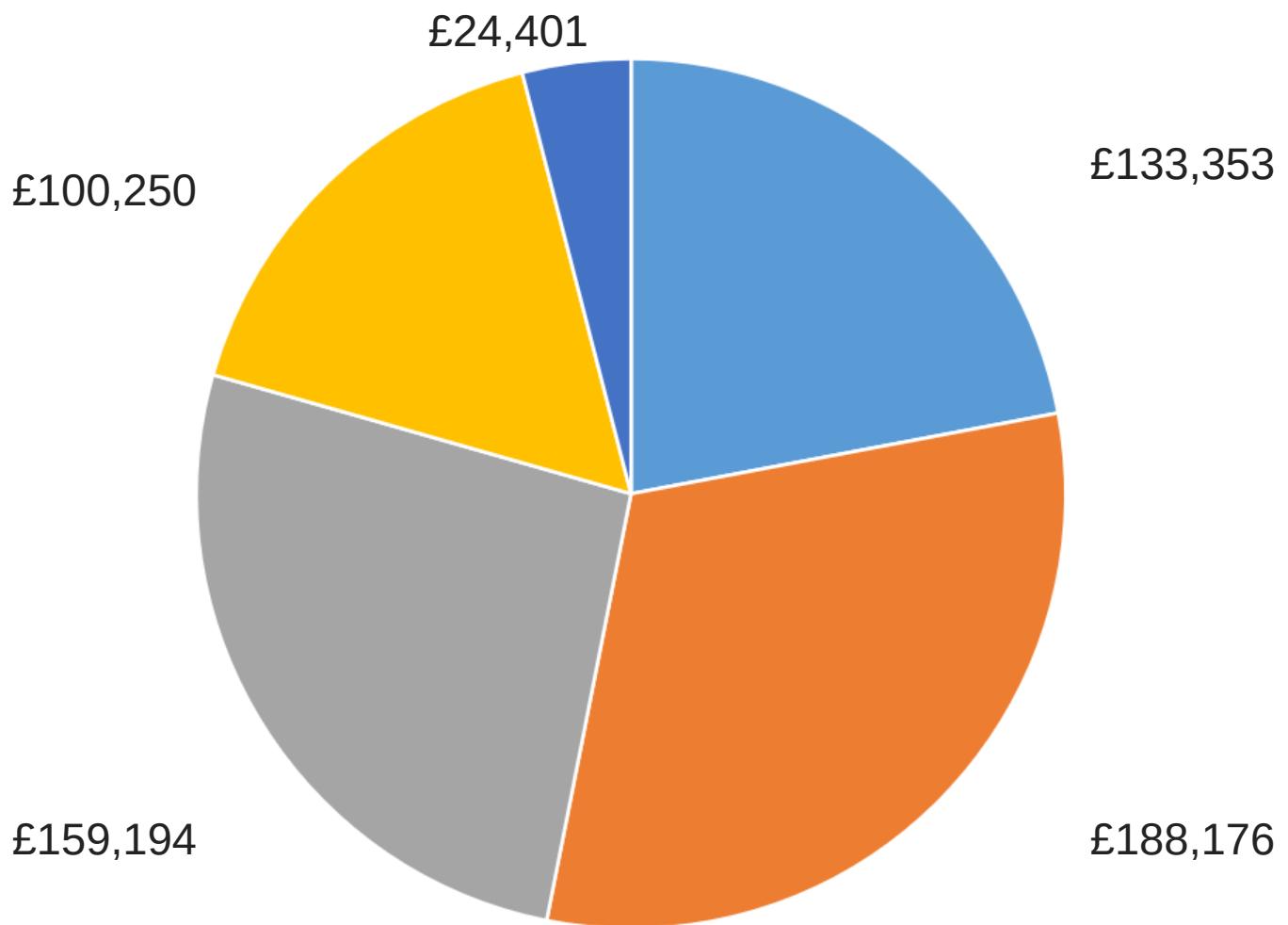
Restricted Donation



Investment Income

Financial Summary

Total Expenditure: £605,374



- █ Fundraising costs
- █ Campaign
- █ Direct Services
- █ Provision of information and advice
- █ Children's Activities & Holiday



For more information visit:
www.sicklecellsociety.org

