



SICKLE
CELL
SOCIETY



2022/3

IMPACT REPORT

2021/2022

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GIVE BLOOD, SPREAD LOVE, ENGLAND

Give Blood, Spread Love, England (GBSLE) engages people with Black African/Caribbean heritage on the topic of blood donation. We aim to increase the amount of ethnically matched blood available to treat people with sickle cell with the lifesaving, and life-enhancing, blood donations they need. We do this through a variety of outreach events and online engagement where we raise awareness of the need for more Black and Mixed donors, tackle the complex fears and myths that exist around blood donation, and sign people up to the blood donation register. We are supported by our amazing volunteer team: the Community

Advocates and the Give Blood Squad.

Covid-19 continued to affect how we delivered GBSLE this year, meaning we held more events online than in person.

We were pleased to be able to recommence our face-to-face information and recruitment sessions in July 2021 and deliver our important messages directly to our target communities.



THIS YEAR, WE:

Attended **9** 'face-to-face' events



speaking with over **500** people



997 people took part in online events

Developed **231** online engagement resources



Recruited **328** new blood donors



Delivered **20** blood donation awareness sessions to organisations across England



Held **14** expert-led online workshops, including, 'How Exchange Blood Transfusions Saved My Life', and 'Break the Stigma: Sickle Cell and Blood Donation'



Ran **6** group blood donation sessions

Produced



4 promotional films

Featured in:



7 online media articles



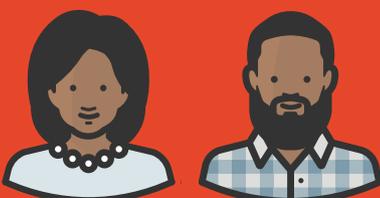
3 radio interviews



2 podcasts



Held **5** volunteer support sessions



Reached over **9500** people directly, and over **66,000** indirectly, via our events and social media
840 hours people have volunteered to the charity

WHAT PEOPLE ARE SAYING ABOUT US

“I love seeing Black and Mixed people give blood as it’s so important for our community that we have blood types that match our own.”

SOCIAL MEDIA FOLLOWER



“I would like to invite you to come on my show at least twice a year to continue to raise awareness.”

RADIO PRESENTER

“Being a volunteer with GBSLE has been a wonderful experience and will continue to be for me, and I wouldn’t change it for the world.”

GBSLE VOLUNTEER



“The sessions you have delivered for us have been brilliant and engaging.”

BLACK-LED COMMUNITY ORGANISATION

“Thank you for such an amazing session. Signing up to donate right now!”

EVENT ATTENDEE

THE SCREENING PROGRAMME

From 1 April 2021 – 31 March 2022 the Sickle Cell Society and UK Thalassaemia Society continued work on the collaborative project with the NHS Sickle Cell and Thalassaemia Screening Programme (NHS SCT Screening Programme) commissioned by the Programme in August 2018.

KEY PROJECT ACHIEVEMENTS:

- Conducted three focus groups with 20 individuals (mothers, fathers and non-parents) who gave valuable user perspective on the communication of newborn screening results.

- Input to the NHS SCT Screening Programme E-learning resource to support health professionals
- Input to three training sessions for nurses, midwives, and health visitors
- Outreach using our specially designed social media screening graphics for World Sickle Cell Day, International Newborn Screening Day and Rare Disease Day.

RAISED AWARENESS OF SICKLE CELL AND SCREENING:



5 Online talks



1 Newspaper article



3 Newsletter articles



1 TV interview

5 Workshops



3 Conferences



PARLIAMENTARY & POLICY WORK

THE SICKLE CELL & THALASSEMIA APPG

The Society has continued working closely with the All-Party Parliamentary Group for Sickle Cell and Thalassaemia (SCTAPPG) through our work as secretariat and with our Parliamentary & Policy Officer. The SCTAPPG aims to raise awareness and prioritise sickle cell disorder and other haemoglobin disorders on the political platform. Accountability is achieved through the SCTAPPG's Chair, Pat Mc Fadden MP and the Deputy Chair, Janet Daby MP.

The key functions of the SCTAPPG parliamentary work:

- Organise and execute four SCTAPPG meetings a year, plus one Annual General Meeting
- Manage SCTAPPG secretariat services
- Communicate SCTAPPG secretariat activity to politicians, stakeholders, Sickle Cell Society (SCS) and other interested parties
- Influence, build and manage effective relationships
- Maintain records of meetings and communications
- Pursue the implementation of the recommendations of the 'No One's Listening' report
- Provide awareness raising sessions on Sickle Cell and the work of the SCTAPPG to various stakeholders and groups
- Direct patient support



Jackie (left) Give Blood, Spread Love Community Advocate



Give Blood, Spread Love Community Advocates



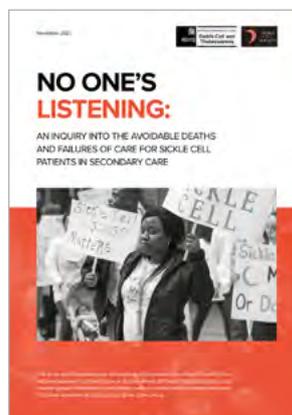
PwC Live Event - Panel

NO ONE'S LISTENING REPORT

The ground-breaking inquiry, led by Rt Hon Pat McFadden MP, Chair of the APPG on Sickle Cell and Thalassaemia, concluded in Autumn 2021. The inquiry was held to get a nationwide picture of sickle cell care in the UK, with both written and oral submissions received from patients, clinicians, researchers and other key individuals. The inquiry found serious care failings in acute services for sickle cell and evidence of healthcare workers' attitudes largely underpinned by racism.

The 'No one's Listening' report, which was based on the inquiry's findings, highlighted evidence of sub-standard care for sickle cell patients admitted to general wards or attending Accident & Emergency (A&E) departments (including a widespread lack of adherence to national care standards), low awareness of sickle cell among healthcare professionals and clear examples of inadequate training and insufficient investment in sickle cell care. The inquiry also found that these concerns have led to a fear and avoidance of hospitals for many people living with sickle cell.

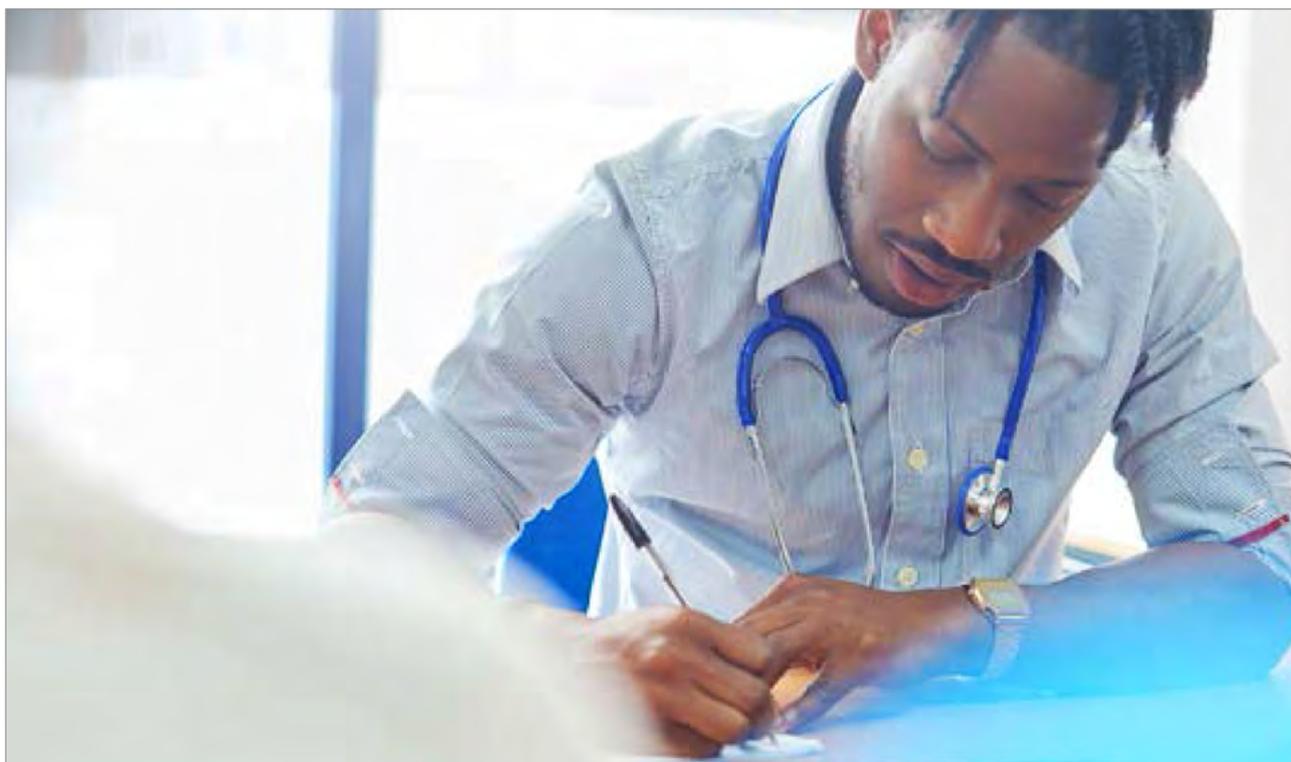
The 'No One's Listening Report' hopes to be a watershed moment for the care of Sickle Cell patients in the UK. Although none of the



THE 'NO ONE'S LISTENING' REPORT HAD A TOTAL REACH OF OVER 61.5 MILLION.

<https://www.sicklecellsociety.org/wp-content/uploads/2021/11/No-Ones-Listening-Final.pdf>

report's findings are new to Sickle Cell patients or their families, the report is an urgent call to action to various parts of our healthcare system and related entities. Whilst the SCTAPPG have celebrated positive responses to the report's release, including a Westminster Hall Debate in Parliament, The NHS Royal Health Observatory's appointment of a clinician to lead work on race and Sickle Cell and a meeting with the Secretary of State for Health and Social Care – there remains a vast amount of work still to be done to ensure the implementation of the report's recommendations.



NO ONE'S LISTENING IMPACT



1 Parliamentary Westminster Hall debate in the Houses of Parliament

3 live Parliamentary Inquiry sessions

2 opinion pieces in The Independent and The Guardian

Over **10** TV and radio interviews



Over **61.5** million people heard about the campaign through broadcast, print and online coverage

Over **200** pieces of written evidence from patients, families, health care professionals and others



CHILDRENS ACTIVITIES

1st April 2021 – 31st March 2022 we have successfully delivered virtual childrens activities for young people with Sickle Cell again. Although we have been running virtually again, that hasn't stopped our young people from having fun and meeting new people. We have even been able to reach children internationally.

THE ACTIVITIES WE HAVE RAN INCLUDED:

Arts and Crafts

Meditation

Confidence building workshop

Comedy show

Quiz Night

African Dancing and Singing

Family Empowerment

Theatre show

Animal Workshop

Baking

Songwriting

Wellbeing workshop

Money management workshop



CHILDRENS ACTIVITIES IN NUMBERS



84 parents who have children with Sickle Cell attended our monthly parent talks



47 young people attended our educational workshops

Young people who joined us from:



1%
Kenya



56% London



5%
Nigeria



40% from out of London



36 young people attended our arts and crafts workshops



71 young people attended all our fun workshops such as confidence building,



8 attended meditation

WE HAVE CONTINUED WITH OUR MONTHLY PARENT TALKS ALSO WHICH OUR PARENTS HAVE FOUND VERY BENEFICIAL. FEEDBACK FROM FAMILIES:

“Thank you for organising these talks.”

“Thoroughly enjoyed this workshop again.”

“Keep the discussions coming it is so helpful. Thank you.”

“Thank you for putting these sessions on and all the work you do for those living with the conditions.”

“Thanks to the organisers.”

”God bless you for your time and input.”

“Thank you for such a valuable, enjoyable event. I really like the fact that these sessions are on zoom as an in person session will mean that some children cannot access it due to weather, health, transport, siblings etc. It is really useful that these sessions are run virtually.”

MEDIA & COMMUNICATION

THE COMMUNICATIONS AND SOCIAL MEDIA OFFICER HAS CONTINUED TO WORK ON GROWING THE SOCIETY'S PRESENCE ACROSS SOCIAL MEDIA PLATFORMS INCLUDING FACEBOOK, TWITTER, INSTAGRAM, AND LINKEDIN. THE SOCIETY HAS SEEN A SIGNIFICANT INCREASE IN SOCIAL MEDIA FOLLOWINGS.



The Society's LinkedIn (Sickle Cell Society) gained over **662** followers.



The Society's Twitter (@SickleCellUK) gained over **1200** followers.



The Society's Facebook (Sickle Cell Society UK) gained over **287** followers.



The Society's Instagram (@sicklecelluk) gained over **1108** followers.



The Sickle Cell Society website received, on average, **19,000** views per month.

www.sicklecellsociety.org

HELPLINE ACTIVITY

TELEPHONE CALL



Total calls for year April 2021 – March 2022:
696 calls

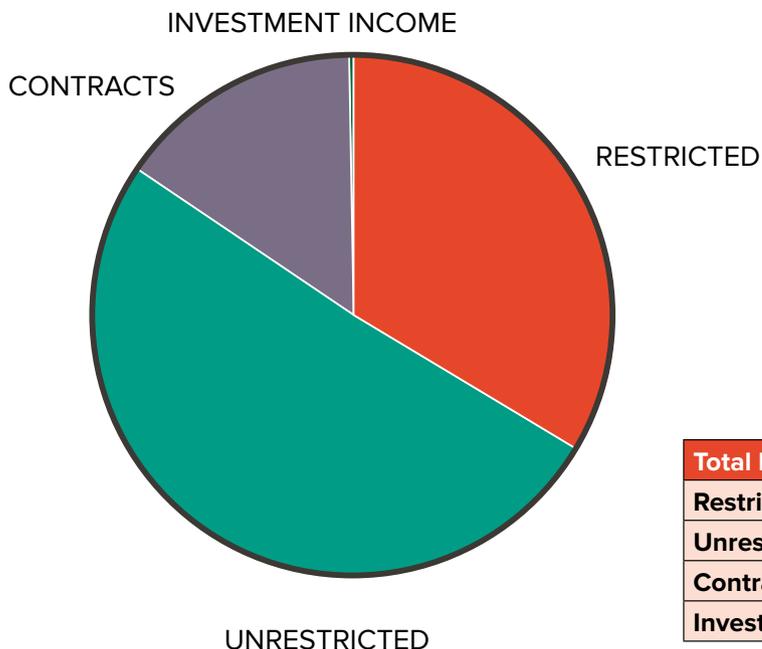
EMAILS RECEIVED



Total emails for year April 2021 – March 2022:
1428 emails

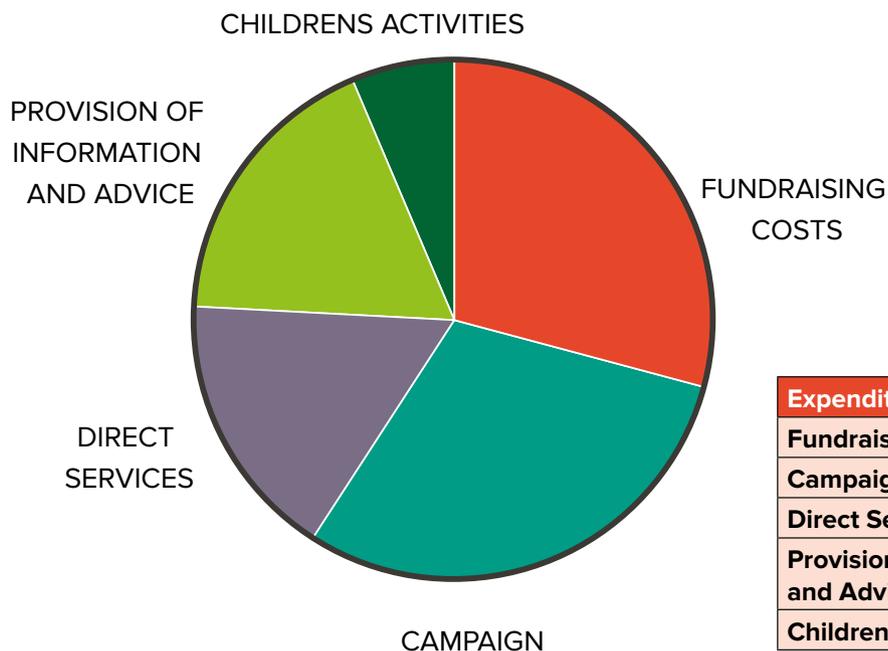
FINANCIAL SUMMARY

TOTAL INCOME



Total Income	£871,742
Restricted	£295,228
Unrestricted	£441,483
Contracts	£134,916
Investment Income	£115

EXPENDITURE



Expenditure	£676,961
Fundraising Cost	£197,588
Campaign	£204,220
Direct Services	£113,397
Provision of Information and Advice	£118,518
Childrens Activities	£43,238

**GIVE
BLOOD
SPREAD
LOVE**

@givebloodspreadlove

#givebloodspreadlove

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