Sickle Cell in South London - Research Report

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SICKLE CELL SOCIETY

A report for Sickle Cell Society

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BIG LOTTERY FUND

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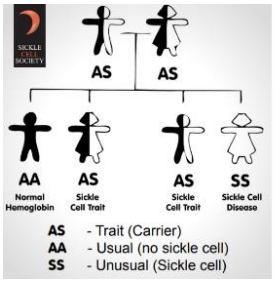
About Sickle Cell Disorder

Sickle cell disorder (SCD) is one of the most common genetic blood conditions in the UK; approximately 15,000 people have SCD and around 270 babies are born with SCD each year. Sickle Cell Disorder predominantly affects people of Black African/Black Caribbean origin for whom there is a 1 in 500 chance of having the condition. The disorder is also present in people of Asian, Middle-Eastern and Mediterranean descent. The numbers of people with sickle cell trait is high within the black population; 1 in 4 people of West African heritage and 1 in 10 people of Caribbean heritage have sickle cell trait. Although it is categorised as a rare disease, sickle cell disorder is the fastest growing genetic disorder in the UK and is increasing in prevalence due to historic and continuing immigration and the rise of 'mixed race' families. SCD causes 'sickling' of red blood cells which can block the body's blood vessels. Known as 'sickle cell crises' – these periods of extreme pain often require emergency hospital admission. Repeated crises can cause chronic fatigue, strokes, tissue and organ damage and early mortality. As well as the physical effects, SCD can result in loneliness, anxiety and depression, partly due to the lack of awareness and understanding of the condition.



About Sickle Cell Society

Sickle Cell Society's mission is to enable and assist people with a sickle cell disorder to realise their full economic and social potential. The Society works in the community to support and develop the wellbeing of individuals and families; raise public awareness of sickle cell through education and advocacy and collaborates with the NHS to strive for excellent sickle cell care for all, regardless of age, social status or geographical location.

"One of the impressive things about the Sickle Cell Society is that it is offering services at a community level but is also able to influence national policy. It has been instrumental in establishing national

standards for the care needs of people with sickle cell disorder while ensuring these are firmly rooted in community needs." (Lisa Weaks, Head of Third Sector at The King's Fund, GSK IMPACT Award, 2018)

Background to this research

South London has the highest concentration of people with sickle cell in the UK, with over 3800 people living or accessing hospital care in this area (National Haemoglobinopathy Registry 2019/20). People living with SCD are often negatively impacted in their day-to-day lives. Children missing school, sport and social activities because of the effects of SCD is widespread. Poor self-esteem, low confidence, isolation, anxiety, and depression are also reported. The negative mental wellbeing of children is often influenced by the difficult transition from child to adult health services.

Similarly, adults also report issues with mental wellbeing as well as problems with employment or access to benefits or suitable housing. This is often due to not understanding their rights or having easy access to the support they need. People with SCD often lack knowledge on self-management issues such as how diet, exercise and other lifestyle factors can help manage their condition. (Sickle Cell Society, South London Link Project, Evaluation, 2019).

In 2019, the Society completed South London Link (SLL), a 3-year Lottery funded programme that offered a diverse range of personal development, practical activities, well-being support and capacity building whilst addressing loneliness and isolation among the sickle cell community.

South London Link aimed to engage with and improve the health, wellbeing and life chances of people living with sickle cell disorder, and their families, in Lambeth, Southwark and Lewisham or attending a Specialist Sickle Cell Service in any of these 3 boroughs, or a hospital that is part of the South Thames Sickle Cell & Thalassaemia Network.

SLL achieved notable successes in its delivery of activities for children, young people and families. The evaluation report on SLL's work (2019) states that 422 people took part in children's social and play events, family workshops and support groups during its first two years. 63% of children who responded to the survey claimed to have made new friends while taking part in family workshops

or children's activities. Similarly, the creation of peer support groups through SLL's work was beneficial for project participants, enabling them to meet people in similar circumstances to themselves, reduce isolation, improve their overall positivity and extend their support networks. 90% of people agreed that because of peer support groups, they felt more positive about building supportive friendships with others affected by sickle cell.

Sickle Cell Society is now taking the opportunity to review the needs of people affected by sickle cell and sickle cell trait in south London. It wishes to verify whether the successful areas of service delivery adopted by South London Link are still required; note emerging areas of interest and concern and consider how the coronavirus pandemic has impacted upon people's support needs.

Sickle Cell Society in South London

The Sickle Cell Society has a history of delivering work in south London and has long established connections with hospitals including, Guys & St Thomas' Foundation Trust, University Hospital Lewisham and Croydon University Hospital, and specialist support centres and wider communities.

In addition to South London Link, in March 2021, the Society completed a successful community engagement project, South London Gives, which engaged black-heritage people on the topic of blood donation. The project served to consolidate and develop the Society's reach in south London and recruited almost 700 new blood donors.

Summary of research approach

Between February and March 2021, we (the report authors) carried out research with people with sickle cell, and their parents, carers and supporters to gather feedback on their needs and preferences for new community service delivery in south London. Engagement methods consisted of an online survey, and two focus groups delivered online due to coronavirus constraints. We disseminated the survey to a wide range of organisations in south London, harnessing the Society's excellent links with hospitals, sickle cell support groups and other voluntary sector organisations.

New links were forged with primary schools in key south London boroughs including Lambeth, Lewisham, Southwark, Greenwich and Croydon. These agencies shared information on our behalf via their social media and directly with their service users.

Limitations of research method

- We used an online survey. However, as not everyone has access to or is comfortable using the internet, we also gave potential participants the option of completing it on the telephone.
- The sickle cell community are often requested to complete surveys, so there may be an element of survey fatigue.
- Challenges with GDPR legislation meant that we could only approach Sickle Cell Society's individual contacts who had 'opted in' to its general communications. We did this through the Society's monthly e-newsletter.
- It was a short intervention with limited timescales, but our findings are supported by the Society's other work, namely, South London Link, the Cast Aside and Forgotten report (2021) and external research such as the work of Simon Dyson of De Montfort University.
- Small sample size: this work represents a snapshot of people affected by sickle cell.
- Our sample profile was predominantly female, so an element of gender imbalance is inevitable.
- Because qualitative research is a perspective-based method of research the responses given in the focus groups are not quantifiable.

Dissemination of survey

We disseminated this **survey** to a range of organisations, support groups and individuals during February and March 2021.

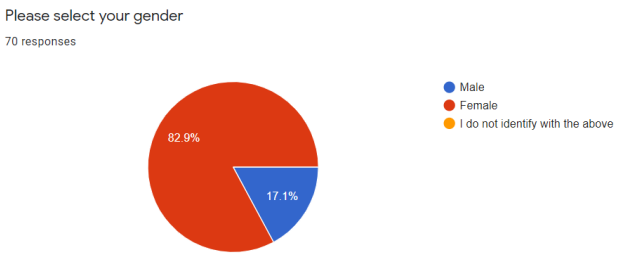
Summary of insights from survey

We received 70 responses.

We reached the majority of respondents- 34%, via contact with schools in the south London area, with a further 43% attained through the SCS online newsletter and social media exposure, 17% from sickle cell support groups and 6% from people attending local hospitals.

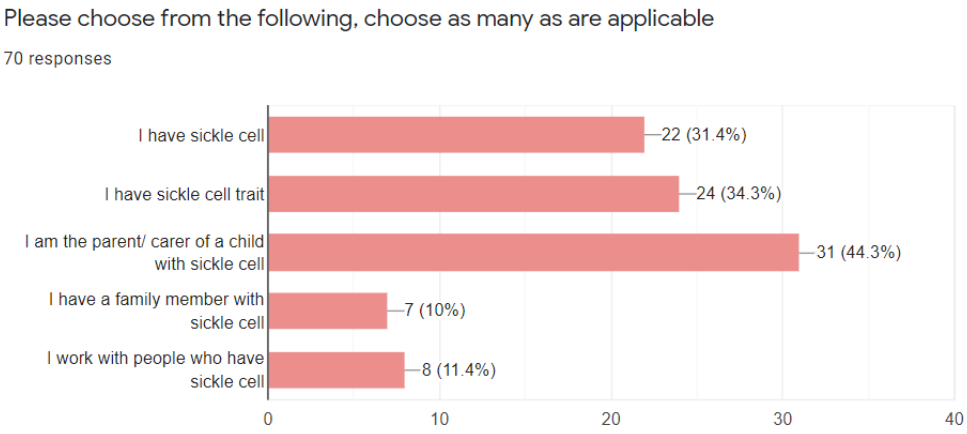
We requested the minimal amount of demographic information needed to inform our research to ensure that people were not put off completing the form due to 'too many' personal details being requested. However, we know that 83% of respondents were female and 44% were parents or carers of children with SCD.

Figure 1



(Image shows breakdown of gender of respondents)

Figure 2



(Image shows sickle cell status of respondents)

In terms of activities and support, 91% of survey respondents expressed an interest in a broad range of areas, ranging from pain management workshops (the most requested) to cultural, creative and health-focused activities, offered either individually or as a group.

Over 77% of respondents expressed the need for increased well-being and emotional support due to the impact of coronavirus, with 53% requesting support to manage feelings of stress and anxiety and 50% asking for easier access to one-to-one support as an outlet for expressing difficult feelings.

In terms of coronavirus and its impact on people's finances and work life, 44 people expressed an interest in support such as access to legal advice on workplace issues. 29% wanted access to business start-up advice; 23% requested finance & money management support and 36% of participants expressed an interest in flexible volunteering opportunities, partly to enable them to develop new skills applicable to work, and to test out nascent areas of interest.

Summary of insights from focus group

10 people took part in 2 focus groups. The focus groups were separated into one for individuals living with sickle cell and one for parents/carers of children with sickle cell.

Participants were identified by opting into the focus group via our survey; we then selected a purposive sample.

As well as having a personal connection to sickle cell, 2 people also worked with those affected by SCD.

In terms of activities and support, responses varied from wanting face-to-face engagement and social interaction with families/individuals, to flexible, virtual options.

In relation to well-being and emotional support, our evidence suggests that peer support would be beneficial for most participants. One participant stated that she would like to be able to access peer support/contact at various key stages in her child's development.

We also heard stories of how lack of awareness, within structures such as the NHS and educational settings, continue to impact the lives of people with sickle cell and their carers, causing stress, frustration and anxiety.

Workplace challenges were also highlighted, with 3 people in the group having experienced difficulties managing sickle cell in the workplace, with 2 feeling they had no option but to leave their jobs due to lack of awareness and support.

Key themes from the research

Awareness

"No allowances or accommodations were offered to help me manage sickle cell at work. If occupational health had been more informed, then this would have trickled down and been a starting point. I felt I had no

other choice than to leave my job. We need to bridge the gap between health advisors and employers." (Focus group participant, February 2021)

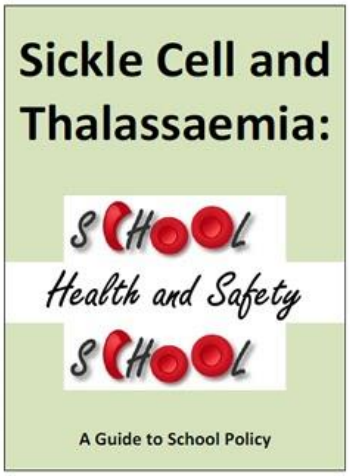
In depth discussion in the focus group illustrated how lack of awareness around sickle cell is still common, both within public structures such as the NHS and educational settings, but also within the wider community. Historically, numerous barriers have hindered national awareness about SCD. For example, one barrier is the low prevalence of SCD compared with many other health problems such as cardiovascular diseases, cancer, and diabetes.

Some participants told us they have not or would be unlikely to disclose their SCD to their employer for fear of discrimination in the workplace due to lack of awareness. One participant told us that although they had worked in their current role for 23 years, it was only later in the pandemic that they felt able to disclose their sickle cell status to their manager and Human Resources. The participant had repeatedly worked through sickle cell crises, taking pain relief in silence, when they had received government advice to shield at home. They also faced other workplace challenges such as working in an office with an air conditioning unit. (Exposure to swift changes in temperature can trigger or exacerbate a crisis.) The subsequent outcome was positive once the participant disclosed their SCD.

For organisations that are made aware of employees' sickle cell disorder, reasonable adjustments are not always being made and one focus group participant told us that due their employer's lack of knowledge and awareness of SCD, maintaining their role in education became challenging, resulting in the participant resigning. Occupational health employees were unknowledgeable of the condition and failed to highlight recommendations, which may have made the role manageable.

Similarly, another participant, also working in education, felt that leaving their employment was the only option as the amount of hospital admissions they had made them feel that their role would soon become untenable. Lack of knowledge or access to legal information and support on workplace issues for people affected by SCD was also highlighted. During the group discussion one participant realised that accessing trade union support may have been beneficial in her situation.

In our focus groups for parents of children with sickle cell, one participant voiced their concerns about the lack of awareness of the school their child attended. It was distressing for this parent to find out that their child had been made to do physical education lessons during a crisis, sometimes be denied access to the toilet, and have chronic fatigue misinterpreted for laziness. A national study of 569 students with sickle cell, conducted by Professor Simon Dyson, a sociologist from De Montfort University and a team of researchers, found many of the respondents reported having negative experiences at school.



"A minority have absences at or beyond levels defined by government as persistently absent. It is important such pupils are not mislabeled by education welfare officers as truant and their parents pressured to account for themselves if such absences are the result of serious episodes of illness." (Professor Simon Dyson, **A Guide to School Policy, 2011**).

One of our focus group participants shared her account of when she took her daughter to hospital during a sickle cell crisis and experienced a lack of awareness of sickle cell from healthcare professionals. The hospital doctors did not know it was an inherited condition or how to best help the child manage their pain.

"The NHS has a duty to deliver the same quality and standard of care regardless of how uncommon or unknown a patient's disease." (John James OBE, Chief Executive of Sickle Cell Society, **The Guardian, 2013)**.

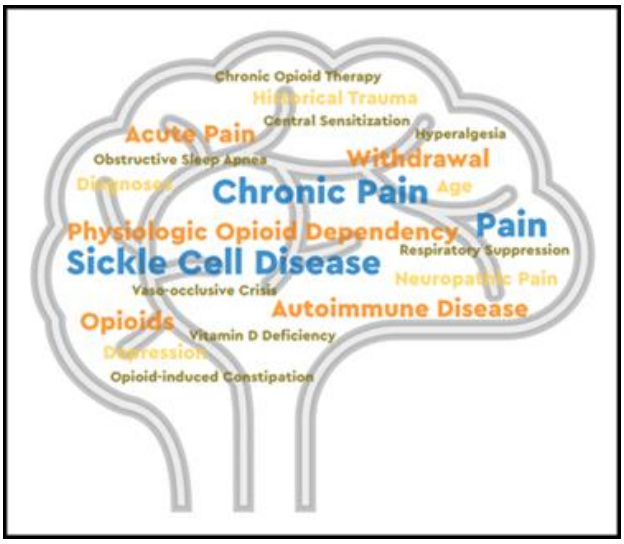
In a recent study, out of 299 UK respondents, 42% said they preferred to manage a crisis at home. 56% had poor experiences at A&E or hospital, while 40% thought 'medical professionals do not understand their disease' (Sickle Cell World Assessment Survey (SWAY), 2019.)

34% of our survey participants have sickle cell trait, and, although typically people with trait do not experience the symptoms found in SCD, some survey respondents did report having physical affects due to their trait status. They

requested more awareness and information on sickle cell trait and its possible implications.

"Myself, my mum and my son all a have sickle cell trait. I feel tired most of the time and we all complain of bone pain especially in the winter when the weather is colder, but I have never seen any information about people with sickle cell trait and symptoms." (Survey participant February 2021)

Although progress has been made and care plans, policies and 'Standards of Clinical Care of Adults with Sickle Cell Disease in the UK' (SCS, 2018) have been produced, it is evident that the knowledge of SCD by healthcare providers still needs to be improved and that within the educational sphere knowledge of SCD is often poor. Education and regular maintenance training, throughout the UK, but particularly in the south London area where SCD is prevalent, is vital to improving the experiences of people affected by sickle cell.



Pain Management

"...chronic negative moods like sadness, anger, or worry amplify your pain at the level of the brain." (Imperial College Healthcare, NHS Trust, 2019)

Opioids have been the primary therapy used to treat both acute Vaso-Occlusive Crisis (VOC) and chronic pain in SCD. However, 74% of our survey respondents stated that they would be keen to be introduced to or further explore alternative pain relief to treat chronic pain.

Focus group participants talked about the effectiveness of alternative therapies in managing psychological and social complications of SCD, such as decreasing feelings of anxiety and depression, enhancing coping skills, and improving quality of life. One participant used a weekly stretch class to manage low-grade chronic pain, which was beneficial both physically and emotionally***, "I used to really look forward to my stretch class… I got to see others on a***

regular basis and it alleviated some of my pain." Another parent participant told us how their child was able to direct their own pain relief from a very young age and could identify the techniques that worked for her, including regular gentle walks.

"Aside from just feeling good, deep relaxation promotes blood flow by causing blood vessels to dilate (become wider), and lowers your stress level - the stress response causes you to release chemicals that make the blood vessels sticky." (Imperial College Healthcare, NHS Trust, 2019).

Well-being activities

89% of survey participants said they would be likely to or would definitely take part in well-being/support activities, ranging from pain relief workshops, arts & crafts, cultural days out to physical activities. Focus group participants all expressed the need for activities to be flexible, enabling them to take part as and when they are able to, allowing for health-related concerns, energy levels, childcare arrangements and work-related factors. Participants wanted activities to be accessible in a variety of ways- online for those who had time or health constraints, face-to-face for those seeking to connect in a group setting, or a combination of both. One participant suggested that taking part and maintaining a regular activity outside of the home would allow for growth and development and said, ***"It's a source of stress release and gives me time to be more reflective."*** Participants highlighted that awareness of sickle cell by instructors/group leaders was important, enabling activities to be sensitively differentiated to the needs of the person without fear of embarrassment. Another important factor which was highlighted was the need for activities to be seasonal, with outdoor/nature activities taking place in the summer months. All focus group participants agreed that being able to take part in a well-being activity promoted feelings of enjoyment, satisfaction and positivity.

COVID- 19

In support of the research by the Sickle Cell and Thalassaemia All-Party Parliamentary Group- the Cast Aside and Forgotten report (2021), where 74% of people with sickle cell said their mental health was affected by the

pandemic- some of our respondents echoed this. Some said they felt social isolation during this period has had a negative impact on their mental health, with the lack of interaction with friends, family, neighbours and health care professionals impacting on their day-to-day living. Some have faced challenges around accessing services and care management due to the reduction of face-to-face appointments in the health care setting.

However, some aspects of the pandemic have offered an unexpected benefit, with one participant discussing the health care their family had received during this time as ‘exemplary’, with a community nurse calling once a week to check in on their child’s health and welfare. Another participant said their child’s crises reduced during the shielding period, while another told us that having to work from home had given them more time to pursue well-being interests and hobbies that they previously struggled to fit in between busy work and home-life schedules.

Some were concerned that the additional support packages offered during Covid-19 would disappear when things return to normal.

Research Recommendations

The wide-ranging findings of this research highlight the need for a broad programme of professionally managed, expert interventions, targeted at people affected by sickle cell disorder and the wider services and support they may interact with, primarily in south London, but also beyond these borders. Our recommendations for service development and delivery are:

Sickle Cell Social Prescribing

The development of a bespoke **social prescribing** service able to respond to the diversity of needs and interests identified in this research, tackling the wider social determinants of health that often negatively affect people with sickle cell. Traditionally used to link people accessing primary care to sources of community support, this model would put an emphasis on self-referral, eschewing the need to go through the health service where individuals may be reluctant to reveal personal support needs. The Society will collaborate with specialist services, including hospitals and local support groups, to raise awareness of the scheme. It will draw upon the Society's existing knowledge of community support routes in the area, and its own extensive information and advice resources to best respond to individual needs, providing support pitched at the right level for each person. Importantly, this approach will avoid duplication of local service provision, rather referring people to proven 'inclusive' services (see below) instead of creating new ones. Those who choose to, will be offered the chance to take part in a structured programme of personal development. The Society will measure benefits for all users in terms of improvement in psychological and physical health and detail wider impact in relation to reduction of pressure on local health infrastructure.

Sickle Cell Support for Organisations

A proactive capacity building service that engages with public and private organisations to develop their awareness and practices on sickle cell disorder. This will enable people with SCD to engage more confidently with such services

and support and have their needs recognised and appropriately met. We have seen that raising sickle cell disorder and trait awareness within organisations, including schools and workplaces, remains a pressing need. Through this service, organisations will be able to access short-term interventions to enable, for example, someone with sickle cell to attend a ‘mainstream’ exercise class, where the leader has been educated in their potential needs. They will also be offered a longer programme of training on sickle cell awareness, resulting in participating agencies being able to publicly evidence their commitment to SCD-inclusive services. Organisations will be encouraged and supported to promote their involvement in the programme, thus raising awareness about sickle cell more broadly, specifically in south London, but with the capacity to reach wider audiences.

Sickle Cell Awareness

A local health awareness and education campaign to bring attention to the prevalence of SCD and trait in south London. Respondents to this research and those to wider Society initiatives, including its Helpline, consistently highlight the lack of general awareness of and discussion about sickle cell both within and outside of highly affected communities. Using south London as a starting point, the Society will scope and execute a programme of awareness, forming a strong coalition of stakeholders and agencies. The south London awareness drive will develop a range of online resources, educational tools and local high-profile campaigns to spark conversations about SCD among targeted segments of the general population. The campaign will measure and monitor levels of awareness and deeper understanding of SCD and its impact on individuals in terms of pain, capacity to work and personal relationships, with the aim of bringing sickle cell out of the margins and into the mainstream. Drawing on the notion of allyship, it will aim to make SCD a community-wide issue and capture public attention through sharing the personal experiences of people who have SCD. This work will also informally direct local agencies to the capacity building service and signpost affected individuals to the Society’s local and nationwide services.

Sickle Cell Connect

A befriending service. The Society will develop an extension to its current Helpline and pilot a telephone/online befriending service matching people affected by sickle cell with a trained befriender with personal experience of SCD. The service will provide emotional support to individuals experiencing isolation and/or mild levels of anxiety and have the capacity to provide regular and ongoing support outside of the remit and capacity of our current Helpline. Trained and supervised Volunteer Befrienders will provide a 'trusted voice', addressing the identified need for easier and more flexibly offered emotional support, separate from the formal, sometimes hard to access, structures currently available. Due to its remotely delivered nature, the Society will consider opening up this service to those beyond south London.

Sickle Cell Family

Regular Family Wellbeing Workshops. Drawing on the Society's experience of successfully running Family Well-being Workshops in 2021 (led by its Children's Activities Leader) and providing online support for parents/carers and children, the Society will build upon this work and increase the number of dedicated family well-being events on offer, with some sessions taking a structured approach and focusing on supporting families as a whole to understand and practise '**the five ways to well-being'**, with the aim of educating, empowering and inspiring them to discover and maximise their own levels of resilience.

Sickle Cell Social and Learning

Social and learning events for individuals and families. This research and previous projects in south London have highlighted the need and interest in the provision of social, leisure, learning and creative activities open to individuals and families, including dedicated activities for children. Evaluation of the Society's South London Link project highlighted how such activities provided vital peer support and served to alleviate feelings of isolation, stress or overwhelm. This strand of the Society's south London work will organise periodical group events enabling people with sickle cell to learn more about

managing SCD, including workshops on pain management; meet and gain informal support from their peers; have fun and try new activities. This programme will be based on the most popular areas of interest identified in our survey.

Sickle Cell Skills

Flexible volunteer opportunities. The programme of services, activities and support set out in the above recommendations are well placed to provide a range of flexible volunteer opportunities to the Society's community of interest. As we have noted, people with sickle cell can often face challenges in maintaining work roles; a structured volunteer offer, aligned to these new services, will support people to develop fresh skills and test interests, partly with a view to exploring new types of work and income streams. However, in line with the outward focused approach of our recommendations, this volunteer offer will also engage with local organisations to build relationships and place volunteers in roles that suit their specific passions and motivations, enabling a more varied and bespoke volunteer matching service responsive to the needs of potential participants.

Sickle Cell Mentoring

The Society has previously run a highly successful **mentoring scheme** aimed at providing emotional, social and physical well-being support to people aged 10 to 25 in east London. The programme was oversubscribed with people from south London (and across almost all London boroughs) requesting access to this vital guidance. A dedicated south London mentee programme will enable the Society to address this expressed need and support young people with sickle cell through some of the key challenges they often experience, including managing the difficult transition from child to adult services, as well as negotiating the challenging demands of adolescent life whilst living with SCD. We found significant interest in the development of such a scheme in south London.

Next steps from this research

Communication

Sickle Cell Society will now present the key findings of this work on its social media platforms, formally summarising the trajectory of the research and setting out recommendations. It will specifically direct the research participants who requested follow up information to these pages.

Immediate adaptations

The report authors have identified that the Society, either fully or partially, can accommodate **two** of the research recommendations into its existing work.

Sickle Cell Family - The Society currently delivers all of its support services remotely due to Covid- 19. This allows for easy inclusion for more potential participants from south London in its current projects supporting children and families. This existing work can draw upon our recent evidence to develop and incorporate new themes, and take the idea of structured well-being support further, testing its efficacy with our target group. Dedicated promotion to south London residents, using the new communication routes identified through this research (most notably, schools in south London boroughs) can be used to alert families to this support and encourage their participation. Furthermore, the Society's yearly programme of Patient Education Days can adopt the theme of family well-being into its calendar of events, providing both theoretical and practical input into this topic. Lastly, despite Covid- 19's multiple challenges, the pandemic has forced many organisations to develop and improve its online practices; stakeholders have become accustomed to being able to access support and information via live and recorded online presentations. We recommend that even when face-to-face work is safe to resume, that the workshops and educational events detailed above continue to be offered online in order to meet this expectation and to maximise reach- to those in south London, but also throughout the UK.

Sickle Cell Skills - The Society hosts a number of volunteers as part of its current projects; in lieu of developing a contiguous, externally focused,

volunteer placement service, the Society can now review its current opportunities for the ‘flexibility’ and ‘skills development’ focus requested by research respondents, asking staff with volunteer management responsibilities to ensure, wherever possible, that their roles meet this request. In addition, the Society can more directly promote its volunteer opportunities to those residing in south London by targeting its calls for volunteer involvement to this group via existing support services in the area, including hospitals providing specialist services and local support groups, and by using the new, successful communication routes initiated through this research.

Priority for funding

The remaining recommendations in this report point to the need for a **South London Sickle Cell Resource,** capable of delivering the multiple work strands identified in this research and supported by a new programme of funding which has the capacity to sustain the breadth and ambition of this work. A central resource or ‘hub’ would enable a coherent, efficient and joined up approach to delivering the diverse but intertwined projects detailed above, encompassing social prescribing; capacity building; awareness raising; befriending; social and learning events and mentoring. It would ensure that the approach undertaken is informed by a thorough overview of specific south London stakeholders; is able to sensitively address the complex and diverse needs of potential service participants, and have the capacity to enhance and create local partnerships with the potential of benefitting all aspects of this planned work.

Conclusion

This research has found that there is a continuing need to provide proven modes of service delivery for those affected by sickle cell in south London – in the form of dedicated activities, support and advocacy for children, families and individuals. Alongside this, we have unearthed new opportunities to test and develop innovative ways to improve the lives of people with sickle cell, with the aim of shifting perceptions of sickle cell disorder on a broad scale and encouraging new audiences in collaborative ventures. Sickle Cell Society has a long history of developing alliances, and engaging with and challenging the

societal structures that impact the lives of people affected by SCD. We believe that the recommendations for funding in this report provide an important route for how the Society can continue to refine, develop and strengthen its work and continue to significantly impact upon the life chances and overall well-being of those with sickle cell and their families.

Further reading

A Guide for Employers and Employees on Work, Employment and Sickle Cell Disorder (SCD), M Berghs & S Dyson, (2019).

About Sickle Cell Disease, Imperial College Healthcare, NHS Trust (2019).

Cast Aside and Forgotten, The Sickle Cell and Thalassaemia All- Party Parliamentary Group, (2021).

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