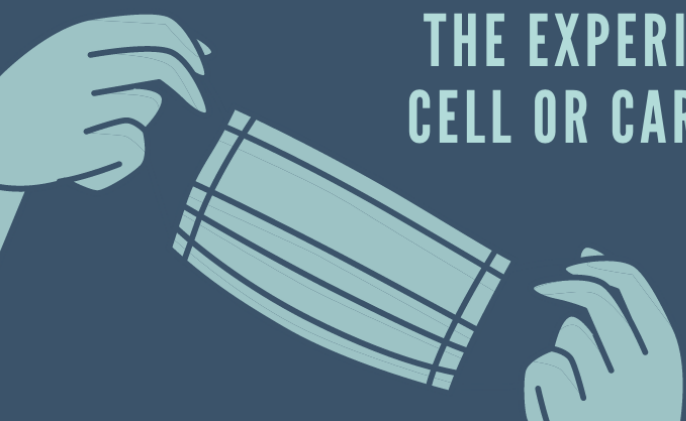


"CAST ASIDE AND FORGOTTEN"

25-34 YEAR OLD PERSON WITH SICKLE CELL
FROM THE MIDLANDS

THE SICKLE CELL AND THALASSAEMIA ALL-PARTY
PARLIAMENTARY GROUP (SCTAPPG) REPORT INTO
THE EXPERIENCES OF THOSE LIVING WITH SICKLE
CELL OR CARING FOR SOMEONE WITH SICKLE CELL
DURING THE COVID-19 PANDEMIC

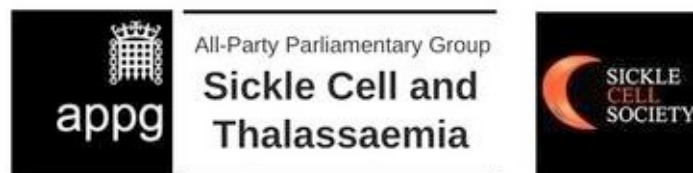


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About us

Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCTAPPG)



The Sickle Cell and Thalassaemia All Party Parliamentary Group (SCTAPPG) raison d'être is to reduce the health inequalities that are faced by sickle cell and thalassaemia patients in the UK. The SCTAPPG secures this by influencing and lobbying policymakers to raise the profile of sickle cell disease and thalassaemia on the political agenda. These efforts are ultimately intended to improve standards of care and address other critical issues, as recommended by the key stakeholders. Members achieve this aim by engaging with parliamentary colleagues, the government, health professionals, and community and patient groups to raise awareness relating to the conditions and needs of patients. The SCTAPPG works in collaboration with The Sickle Cell Society striving to reflect the concerns of their membership and to act as a vehicle for change.

The Sickle Cell Society (SCS)

The Sickle Cell Society (SCS) is the only national charity in the UK that supports and represents people affected by sickle cell disease to improve their overall quality of life. The Society's mission is to enable and assist

individuals with a sickle cell disorder to realise their full economic and social potential. The Sickle Cell Society (SCS) has been in existence since 1979 and has amassed a wealth of experience in sickle cell not only in the U.K. but through its network and association with other countries.



“Cast Aside and Forgotten About” – Report into the experiences of those living with sickle cell or caring for someone with sickle cell during the COVID-19 pandemic

Background

At the beginning of this COVID-19 pandemic, the sickle cell community much like the rest of the United Kingdom was shaken to its core, and what predominantly drove this quake was the fear of the unknown. The inability to grasp what was to come next and the accompanying trepidation that came with it resulted in an enormous amount of anguish and apprehension amongst our service users. The Sickle Cell Society looked to stem this outpouring of anxiety by providing expert advice and support through the plethora of services it offers, whether that's through its helpline which was inundated with queries, or its website providing the most up-to-date guidance. The pandemic had an unsteady start for those with sickle cell community when the NHS's *People at high risk (clinically extremely vulnerable)* list included Homozygous sickle cell disease but failed to include other genotypes of sickle cell disease. After this oversight was rectified, it was then discovered through countless anecdotal accounts that those with sickle cell trait were being told erroneously they were also being classed as *clinically extremely vulnerable*. These two incidents failed to reassure the sickle cell community, and hence we knew it was crucial that more must be done by those outside central government to safeguard those living with SCD.

Consequently, in order to determine the multi-faceted impact that the COVID-19 pandemic has had, is having, and will continue to have on the sickle cell community, the SCTAPPG commissioned a survey into the ramifications that coronavirus would have on the sickle cell community and their primary care givers. We believed that this would serve as an opportunity for the SCTAPPG to compile a report into the experiences of those living with sickle cell in these uncertain times. Amongst a host of objectives, it was key to use this data to determine whether those living with sickle cell or caring for someone with sickle cell disorder are receiving all the information required, and whether the government guidance is suitable for their circumstances. The survey was launched on 28th of May 2020, and then distributed to sickle cell service users through the Sickle Cell Society membership. In order to increase the reliability of results the survey was widely disseminated throughout patient groups and clinical networks to garner as many responses as possible. We had considerable participation with 186 self-selected respondents, primarily through accessing the networks of patient groups and encouraging them to share the questionnaire.

The report aspires to provide you with the prevailing issues that are affecting our service users during this pandemic as well as, in respondents' own words, offering you an insight into the reality of living day-to-day during the government lockdown. It also seeks to examine this COVID-19 pandemic through the lens of the structural injustices that exist which have only served to exacerbate the plight of our service users. The key findings have aided the SCTAPPG to be in a position to make a host of substantive policy recommendations in order to ensure the safety of this clinically vulnerable cohort going forward.

Literature Review

COVID-19 impact on the BAME Community

COVID-19 has illuminated many underlying issues within the BAME community regarding access to health and social care and the disproportionate rate of mortality compared to those considered BAME. This seeks to provide a background on this important matter, outline the precise impact that COVID-19 is having and illustrate the policies being put in place by government and NHS England to mitigate these issues. This will serve to inform this report when we shine a spotlight on the sickle cell community.

Background

Workforce

Social Care¹

- Black, Asian and Minority Ethnic (BAME) workers made up 21% of the adult social care workforce. This was more diverse than the overall population of England (14% BAME).
- Black/African/Caribbean/Black British background (12%) accounted for over half of the BAME adult social care workforce. This compares to 3% in the overall population of England
- London has the most diverse social care workforce (67% BAME)

NHS and Mental Health Services²

- Among NHS staff whose ethnicity was known, 4 out of 5 (79.2%) were White (including White ethnic minorities), and 1 in 5 (20.7%) were from all other ethnic groups
- Pakistani, Indian and black African men are respectively 90%, 150% and 310% more likely to work in healthcare than white British men.
- Among the non-medical workforce, staff from the Asian, Black, Mixed and Other ethnic groups made up a smaller number of those at senior grades and the 'very senior manager' grade than at the support and middle grades
- A significant proportion of the mental healthcare workforce (for Psychiatrists- 39% of RCPsych members, and 33.3% of doctors on the General Medical Council specialist register for psychiatry) is from a BAME background.

BAME Mental Health³

- Research shows that BAME individuals are 40% more likely to access mental health support via a criminal justice route rather than voluntarily seeking and accessing support
- Figures show that black women are more likely to experience a common mental disorder than white women
- Another report, found that those from a South Asian background were reported as showing the least improvement after an Improving Access to Psychological Therapies (IAPT) referral, which provides evidence-based treatments for people with anxiety and depression. -

¹ <https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-state-of-the-adult-social-care-sector-and-workforce-2018.pdf>

² <https://www.ethnicity-facts-figures.service.gov.uk/workforce-and-business/workforce-diversity/nhs-workforce/latest>

³ <https://www.bda.uk.com/resource/improving-the-quality-of-care-for-ethnic-minority-communities.html>

- People who identify as White British were around twice as likely to be receiving some form of treatment for mental or emotional problems from 2015/2016.

Black Men and Women⁴

- The Adult Psychiatric Morbidity Survey (APMS) found that Black men were more likely than their White counterparts to experience a psychotic disorder in the last year.
- Risk of psychosis in Black Caribbean groups is estimated to be nearly seven times higher than in the White population.
- Detention rates under the Mental Health Act during 2017/2018 were four times higher for people in the 'Black' or 'Black British' group than those in the 'White' group.
- Black men were reported to have the highest rates of drug use and drug dependency than other groups.
- Whilst the White Caucasian population experienced the highest rates for suicidal thoughts, suicide rates are higher among young men of Black African, Black Caribbean origin, and among middle aged Black African, Black Caribbean and South Asian women than among their White British counterparts.

Health Inequalities⁵

Across a plethora of health outcomes there is a noticeable impact caused by ethnicity, these include:

- Type 2 diabetes is 3.5 times more prevalent in South Asians than Europeans
- In the UK, men of Black African and Black Caribbean descent are three times more likely to develop prostate cancer than white men of the same age.
- Infant mortality in England and Wales for children born to mothers from Pakistan is double the average.
- Young Asian women are more than twice as likely to commit suicide as young white women.
- South Asian people are 50% more likely to die prematurely from coronary heart disease than the general population.
- Asian women aged 65 and over have the highest rate of limiting, long-term illness (64.5% compared to 53% for all women aged 65 and over).
- The prevalence of stroke among African Caribbean and South Asian men is 40% to 70% higher than for the general population
- 90% of children in the UK have visited a dentist. This compares with approximately 40% of Bangladeshi and 60% of Pakistani children.
- National patient surveys show lower levels of satisfaction amongst BAME patients: GP Patient Survey results 2018/10: Patients very satisfied with the care from their GP or health centre by ethnicity: Irish 60%, British 56%, compared with Chinese 27%, Bangladeshi 28% and Pakistani 29%

⁴ <https://www.mentalhealth.org.uk/a-to-z/b/black-asian-and-minority-ethnic-bame-communities>

⁵ <https://www.bdct.nhs.uk/wp-content/uploads/2016/12/Race.pdf>

COVID-19 Impacts

Institute for Fiscal Studies Report⁶

- The death rate among British black Africans and British Pakistanis from coronavirus in English hospitals is more than 2.5 times that of the white population, according analysis by the Institute of Fiscal Studies.
- They also found that deaths of people from a black Caribbean background were 1.7 times higher than for white Britons.
- Examining the possible reasons, it says that a third of all working-age Black Africans are employed in key worker roles, 50% more than the share of the White British population.
- Concerns have been growing about the disproportionate impact of coronavirus on black, Asian and minority ethnic (BAME) people since figures published earlier this month showed that 35% of almost 2,000 Covid-19 patients in intensive care units in England, Wales and Northern Ireland were non-white, compared with 14% of the population of England and Wales, according to the 2011 census.

Kings Fund⁷

- People from ethnic minority backgrounds constitute 14 per cent of the population but, according to a recent study, account for 34 per cent of critically ill Covid-19 patients and a similar percentage of all Covid-19 cases.
- Of 119 NHS staff known to have died in the pandemic, 64 per cent were from an ethnic minority background.
- Language barriers also provide a restriction to access. These issues will be compounded by the COVID-19 no visitor policy, individuals will be less able to communicate symptoms and needs. For example, the assessment of pain scales can be culture-dependent/

Public Health England Report – Released 2/6/20⁸

On 16 April the UK government announced a formal review, by Public Health England, into the higher death rates. On the day of its publication it was announced that Liz Truss would lead a further review. Some of the key findings were:

- An analysis of survival among confirmed COVID-19 cases and using more detailed ethnic groups, shows that after accounting for the effect of sex, age, deprivation and region, people of Bangladeshi ethnicity had around twice the risk of death than people of White British ethnicity.
- People of Chinese, Indian, Pakistani, Other Asian, Caribbean and Other Black ethnicity had between 10 and 50% higher risk of death when compared to White British. These analyses did not account for the effect of occupation, comorbidities or obesity.
- Black males were 4.2 times more likely to die from a COVID-19-related death than White males
- The relationship between ethnicity and health is complex and likely to be the result of a combination of factors.

⁶ <https://www.ifs.org.uk/inequality/chapter/are-some-ethnic-groups-more-vulnerable-to-covid-19-than-others/>

⁷ <https://www.kingsfund.org.uk/blog/2020/04/ethnic-minority-deaths-covid-19>

⁸ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/889195/disparities_review.pdf

- Firstly, people of BAME communities are likely to be at increased risk of acquiring the infection. This is because BAME people are more likely to live in urban areas, in overcrowded households in deprived areas and have jobs that expose them to higher risk
- People of BAME groups are also more likely than people of White British ethnicity to be born abroad, which means they may face additional barriers in accessing services that are created by, for example, cultural and language differences.
- People of BAME communities are also likely to be at increased risk of poorer outcomes once they acquire the infection. For example, some co-morbidities which increase the risk of poorer outcomes from COVID-19 are more common among certain ethnic groups.

Reaction

- PHE was criticised for simply restating the increased mortality highlighted by other research without explaining the reasons for the stark disparity, or making recommendations to tackle it. The British Medical Association (BMA), which represents Britain's doctors, described it as "a missed opportunity" to instigate urgent action.
- Sadiq Khan, the mayor of London, demanded a full-blown public inquiry, with ministers committed to implementing its conclusions.
- BMA lamented the report's lack of practical guidance on how to better protect people of BAME origin.
- A Health Service Journal report published on Tuesday night claimed that the government had removed a key part of the review. It said a section was missing that appeared in a draft version circulated last week with responses from more than 1,000 organisations and individuals, many of them suggesting that discrimination and poorer life chances played a part in greater Covid-19 risk for BAME Britons. PHE and the health department both denied the story.

Build Back Fairer: The COVID-19 Marmot Review – released 16/12/20⁹

- BAME Mortality risks from COVID-19 are much higher among many BAME groups than White workers in England. These BAME groups are disproportionately represented in more deprived areas and high risk occupations; these risk factors are the result of longstanding inequalities and structural racism. This does not fully explain COVID-19 risk, there is also evidence that much of the BAME workforce in highly exposed occupations are not being sufficiently protected with PPE and safety measures.
- BAME groups are experiencing higher rates of mortality from COVID-19. This is related to their disproportionate experience of high-risk living and working conditions. These are partly the result of longstanding impacts of discrimination and exclusion associated with systemic racism. There is also evidence that the BAME workforce in highly exposed occupations are not being sufficiently protected with PPE and safety measures.

⁹ <http://www.instituteofhealthequity.org/resources-reports/build-back-fairer-the-covid-19-marmot-review/build-back-fairer-the-covid-19-marmot-review-full-report.pdf>

Policy Response

Moving BAME people away from frontline – Risk Assessments¹⁰

- Drive to risk-assess minority ethnic workers aims to reduce higher death rate from Covid-19
- NHS staff from black, Asian and minority ethnic backgrounds will be given different roles away from the frontline under plans to reduce their disproportionately high death rate from Covid-19.
- BAME personnel should be “risk-assessed” and reassigned to duties that leave them at lesser risk of contracting coronavirus, under guidance set out by NHS bosses in England.
- These requests were spelled out in a nine-page letter, from NHS improvement’s chief operating officer, Amanda Pritchard which was sent to those running NHS care organisations across England.
 - *“In advance of their report and guidance, on a precautionary basis we recommend employers should risk-assess staff at potentially greater risk and make appropriate arrangements accordingly.”*
- It does not outline what specific measures they should take to protect the safety of their BAME staff
 - Some NHS trusts have already recognised the extra risk faced by their BAME workforce and taken steps to reduce that. For example, Somerset NHS foundation trust, has classed them as “vulnerable and at risk”. It has begun asking BAME staff if they feel safe at work, giving them priority for testing and ensuring that they undergo a “fit-test” in order to wear an FFP3 ventilator mask, which all health professionals working with Covid-positive *patients are meant to use as a key part of their personal protective equipment.*

NHS England and NHS Confederation launch expert research centre on health inequalities¹¹

- NHS England and the NHS Confederation have confirmed the creation of a new centre to investigate the impact of race and ethnicity on people’s health.
- The NHS Race and Health Observatory, which will be hosted by the NHS Confederation, will identify and tackle the specific health challenges facing people from BAME backgrounds.
- It comes amid significant concerns about the particular impact of the COVID-19 virus on people from black, Asian and ethnic minority (BAME) backgrounds.
- The Observatory will involve experts from this country and internationally and will offer analysis and policy recommendations to improve health outcomes for NHS patients, communities and staff.
- The founding of the NHS Race and Health Observatory comes after the latest assessment of race equality in the NHS

¹⁰ <https://www.theguardian.com/world/2020/apr/30/nhs-bosses-say-bame-staff-should-be-risk-assessed-to-cut-covid-19>

¹¹ <https://www.england.nhs.uk/2020/05/nhs-england-and-nhs-confederation-launch-expert-research-centre-on-health-inequalities/>

Engagement with staff and staff networks

- Within the NHS Engagement with staff and staff networks are being strengthened and prioritised to enable NHS decision makers to hear and learn from NHS people's lived experience. Meaningful dialogue and active listening will result in real change across the NHS.
- NHS continue to engage with existing BAME, faith and other staff networks and other staff groups as well as senior regional leads on importance of equality and inclusion.
- They have started a series of webinars with staff networks across organisations and disciplines using existing BAME, faith and other networks. The first was attended by more than 240 heads.

Rehabilitation and recovery

- The NHS nationally and locally has developed a range of wellbeing support to care for and protect everyone, whether at the front line or in supporting services.
- A bespoke health and wellbeing offer (including rehabilitation and recovery) for BAME colleagues is being created in addition to the range of resources already available
 - The specificities of this are yet to be spelled out

What providers can do?

Kings Fund Suggestions¹²

The Kings Fund suggested what staff within organisations can do to help mitigate these issues:

"First, we must recognise the role that white staff can and should play. It may be hard for white people to accept that we are all part of the problem. Almost all of us as individuals will say we are not – 'it's other white people', but, in reality, we are all part of the problem and we should all be part of the solution."

Every white member of health and care staff can commit to:

- Treating those from different backgrounds with greater civility, respect, and compassion
- Ensuring co-workers feel the climate for inclusion has markedly improved within six months
- Learning about the research evidence on the impact of racism and discrimination on health, life chances and mortality
- Intervening when they observe discrimination, incivility or racism towards colleagues
- Becoming a champion of equality, positive diversity and inclusion and encouraging others to do the same
- Renewing these objectives every six months.

Every leader can commit to both those objectives and others by:

- Positively and overtly valuing equality, diversity and inclusion both for its own sake and for its impact on care quality and staff wellbeing
- Practising compassionate leadership – attending to those they lead, understanding their challenges, empathising and helping
- Providing stretching project and career opportunities for staff from minority ethnic groups while providing good support

¹² <https://www.kingsfund.org.uk/blog/2020/04/ethnic-minority-deaths-covid-19>

- Learning about the research evidence on how diversity is associated with team and organisational effectiveness and innovation in health care
- Creating fair and just cultures in their teams and organisations
- Mentoring and coaching staff from minority ethnic groups and creating opportunities for reverse mentoring.
- Assessing their performance as inclusive leaders ensuring everyone, they lead feels included by their leadership
- Ensuring all team members commit to the objectives above and receive regular supportive feedback.

COVID-19 and Sickle Cell

Covid-19 & haemoglobinopathies: National data collection - National Haemoglobinopathy Panel¹³

Since the start of the COVID-19 pandemic, some groups of patients have been classed as 'clinically extremely vulnerable' and advised to 'shield' in order to avoid becoming infected. Many patients and patient support groups would like know how frequent and how severe COVID-19 has been for people with inherited anaemias, including:

- Sickle cell disease
- Thalassaemia (transfusion dependent and non-transfusion dependent)
- Diamond Blackfan anaemia
- Congenital dyserythropoietic anaemia
- Congenital sideroblastic anaemia
- Pyruvate kinase deficiency (with and without a spleen)
- Hereditary Spherocytosis (with and without a spleen)
- Other types of rare inherited anaemia

The panel reviews guidance issued by NHS England and advises NHS England and patient support groups about specific COVID-19 risks. Hospitals across the England have sent in anonymised data to the group regarding the number of cases of COVID-19 and what happens to people who get it.

How many people with inherited anaemias have had Covid-19?

Up to the 23rd September, 263 people had been reported with proven or suspected COVID-19. Of these, 229 were adults and 34 children. Most had sickle cell disease, but a small number of thalassemia and rare inherited anaemia patients were also affected.

How many people were admitted to hospital?

Almost 70% of patients were admitted to hospital (about 179 people), and the rest managed at home. There were slightly more women than men affected.

Of the patients admitted to hospital, about 10% needed NIV Support and 6% needed intubation.

What was the outcome for people admitted to hospital?

The picture is not yet complete, because some people are still being treated for COVID-19.

¹³ Covid-19 & haemoglobinopathies: National data collection, National Haemoglobinopathy Panel, Ralph Brown, Mamta Sohal, Josu de la Fuente and Mark Layton, Fred Piel

The results show that of the 263 patients (23rd September):

- 244 have recovered (93%)
- 15 have died (6%)
- 4 are currently inpatient or unknown (1%)

The people who died were more likely to have other medical problems such as heart disease, cancer, kidney disease, diabetes and high blood pressure. The panel has said it's too early to say whether patients with inherited anaemias do any worse than the general population. Children with sickle cell disease, thalassaemia and rare anaemias who do not have other risk factors, do not seem to be at increased risk of having severe disease. It is important to note that there have been many people with inherited anaemias who have had few or no symptoms with their COVID-19 infection, and who have fully recovered

Key Survey Findings

- **50.5% of respondents informed us that the COVID-19 had affected their access to healthcare services in their locality.** It is a chilling statistic that just over half of all respondents revealed that their usual health pathways were being disrupted by the pandemic.

This failure to access healthcare services will most likely be in direct contradiction of doctors' orders - who are best placed administer the most effective treatments and provide advice on healthcare needs. There was a general consensus that cancellation of GP service provision/outpatient appointments/annual consultations/ planned surgeries/ planned routine check-up's/scans is a prevailing issue. Respondents had an overwhelming sense of fear and trepidation about the future, and how these delays and missed appointments will affect their health outcomes. From renal to haematologist appointments, it is apparent there is distress and panic that services users are not being afforded the opportunity to effectively manage their condition by using the host of services they require. The cohort feels a sense of neglect with people lamenting that they have not had a blood test for months. **Of those who hadn't been able to access all their healthcare services, 20.5% of that cohort had reported this had itself brought on a crisis.**

Furthermore, the nature of having to conduct appointments over the phone has resulted in cases whereby service users have felt an inability to be able communicate effectively one's condition. This has people feeling helpless to improve and manage their condition. What's more, a reliance on support networks to carry out visits to the chemists/pharmacies puts those without those very networks at risk of failing to adhere to medical advice through no fault of their own.

Respondents were given the opportunity to elaborate on their experiences in free text responses:

"Outpatient appointments have moved to phone calls, GP appointments cancelled, I have not been able to go to chemists due to shielding, so I had to manage pain for a month while waiting for my next check-up."

"There was a delay of 3-4 months where I was not able to receive my 5-year pneumovax injection, nor could I see my Haematology team."

"Harder to get prescriptions and also getting medication delivered on time to manage my sickle cell. I have not been able to have regular blood tests to help monitor my condition."

"I can't receive blood exchanges because I don't have access to theatres for a main line insertion."

"My GP refused face to face appointment so I ended up in hospital with severe pneumonia because they didn't inspect my chest."

"I find it harder to access non-sickle related medical support as it takes so much longer due to back log etc e.g. waiting for surgery to remove a pre-cancerous lesion which has increased my level of anxiety as I haven't heard back and not sure how to chase it up and that's just one example."

"I'm not sure how I'm going to get a new prescription for Hydroxyurea or any of my other medication. And those not fortunate enough to have support networks having to take the biggest risk of them all and fend for themselves."

- **16.7% of respondents reported having or knowing someone living with SCD had COVID-19.** There were some harrowing anecdotes of personal tragedies along with disillusion amongst respondents registering frustration at recounting people they know being sent home prematurely. There was a general consensus that services users felt that having SCD sometimes felt hindered them getting treatment as they were vulnerable to transmission within hospitals.

Respondents were given the opportunity to elaborate on their experiences in free text responses:

"A five year old child with sickle cell anaemia passed away. The family was known to a sickle cell support group that I belong to. This loss made me and other care givers very anxious and had a negative impact on my mental health. The trauma and the bereavement caused me to experience panic attack due to anxiety around my children having sickle cell anaemia."

"The person recovered thankfully! They were initially sent home after going to hospital, but when things got worse at home they called for an ambulance which took them to hospital. They recovered in hospital but ended up with very bad lung scarring."

"I had COVID-19 and was seriously ill. Was admitted to hospital and spent a few days there. Did not need to go to ITU thankfully. But it took me about 5 weeks to get better physically. I am still dealing with the emotional scars and I'm sure they will never disappear."

"Friend with SCD got sent home from hospital with COVID and almost died. Her teen son called 999 just in time. She still hasn't fully recovered and its frightened fellow sufferers."

"My new born and I had covid it was a traumatic for me but we pulled through."

"A patient I knew died from covid-19"

- **Understandably, a staggering 94.1% of respondents felt either worried or very worried about the risk of the health consequences from COVID-19.** To describe the trepidation and fear that respondents expressed would be an understatement. The anguish and trauma that service users have undergone is beyond words. Most members expressed awareness of how their condition could be a significant factor in them being unable to survive. They elaborated on how their co-morbidities could also hinder their ability to recover from the virus (respondents spoke of respiratory and immunological apprehensions). However, it must be stressed that it has yet to be substantiated whether SCD does have a material impact on mortality from COVID-19. The cohorts legitimate concern is attributable, justifiably, to a fear of the unknown. In turn, what is beyond reasonable doubt is the anxiety and distress that the community is going through during this pandemic, which is wreaking havoc with service's user's psychological and physiological health.

In addition, participants allayed fears around long COVID and how those with SCD who contracted would fair in the reported debilitating effects of the virus months after being infected.

"I had pneumonia last year and other severe crisis due to infections so spent a lot of time in hospital. I still have not completely mentally recovered from this so am very anxious about getting more ill and being severely ill from COVID-19."

"Not so much worried but cautious. Because I don't have a spleen so my immune system is very low."

"I fear my partner's chances of surviving COVID-19 are low."

"I'm made to understand that Covid affects both the immune system and respiratory organs. My lungs have diminished lung function capacity and a pretty low immune system."

"Not only does my husband have Sickle-Cell SS he has Beta Thalassaemia, G6pd Deficiency, myocarditis. We know would be miracle if survives."

"I'm worried because if I was to get covid, would I survive? My immune system is so weak and it just scares me because I don't know if my body would be able to handle it. So many factors contribute to my Covid anxieties e.g. my job, my health (immune system and respiratory system not up to par), my child (the possibility of her bringing it home to me from school) etc."

"I feel very confused by the mixed messaging, and can't find any information that is helpful in alleviating my fears. Since the pausing of the shielding programme, my worries have significantly increased."

"I fear if I catch it, it could kill me."

- **The bulk of participants (88.5%) felt either satisfied or very satisfied with the information available to them about COVID-19 and its relation to sickle cell and sickle cell trait.** The majority felt that they were content with the current information that had been disseminated, and that as individuals with sickle cell, they knew they were classed as clinically vulnerable from COVID-19. For instance, **92.5% reported that they'd received a letter or text instructing them from the government to shield as one of the vulnerable groups. In addition, 50% of respondents also outlined how they'd also been contacted by their local authorities/allied health professionals.**

Nevertheless, there were anecdotes documented by respondents about cases of no contact being made whatsoever, and a general consensus that more engagement was required via follow-up letters etc. This evidence shows that, if employed, a joined up multi-agency approach is effective - and it does become apparent that the remaining 50% did not have the same level of engagement. Though on the whole, contact has been made, the variety of sources and level of contact seems sporadic, disjointed and bespoke and not uniform enough as people are slipping through the net. It must be of paramount concern that all respondents are and feel fully informed about how they must conduct themselves during the pandemic to keep themselves safe.

A plethora of respondents highlighted the sickle cell trait debacle whereby they were accidentally left on those who are deemed clinically extremely vulnerable from COVID-19. This mistake proved to unnecessarily cause an enormous amount of confusion and distress to those concerned.

Some expressed concerns about the generic, vague, ambiguous and mixed messaging emanating from the government. Epitomising this information problem was service users

who felt they had a Catch-22 situation: choosing to protect their health or depriving their child of schooling. **However, 57% of respondents accessed information from the Sick Cell Society website which over the course of the pandemic has had the most up to date guidance. The content of which was well received with a very sizable 88.4% of those who accessed the material being either satisfied or very satisfied with the advice and support outlined on its website.**

Respondents were given the opportunity to elaborate on their experiences in free text responses:

"The government, my GP, and sickle cell clinic failed to contact me. I had to call several times to all three to ask why I was not informed in any form. All was unsure. I was contacted on 24th April weeks into lockdown from my GP to apologise that I had not been told or highlighted to the NHS as vulnerable. Up to date my parents of the same address and GP who are both sickle trait, diabetic and over 70 have not been contacted!"

"The information is very generic."

"There has been limited information from the government since the lockdown was relaxed. In particular about how people classified as vulnerable such as people living with sickle cell anaemia should keep themselves safe. Messages are confusing around sending children to school or returning to work. There haven't been clear messages about how to protect the children living with the sickle cell anaemia condition."

"Still confusion over SC trait! Too vague."

"Psychological perspectives has been down played if not overlooked. Extra funding to address additional costs. Communication breakdown between professionals and lack of follow up letters. Not being able to attend funeral and pay your last respect. Or celebrate birthdays and other special occasions. Lack of touch, hugs and kisses."

"I'm dissatisfied because we don't know how it works with sickle cell. Whether or not having sickle cell is a greater complication than anyone else contracting the virus. Also it is hard to determine how COVID-19 works in the body whether it causes more crises or has no impact on that."

- **74.2% of those with SCD and their carers are experiencing an impact on their mental health because of social distancing and self-isolation.** We are sleepwalking into a mental health crisis; in very striking testimony it is abundantly clear that the psychological toll the pandemic is having on those who are required to shield is enormous and was underestimated. Along with the everyday anxiety of having or caring for someone with the condition, this pandemic has exerted an incredible upsurge of trauma in the SCD community. From the confusion around SCT guidance, the loneliness, and uncertainty about when the panic will be over. This cocktail of damaging factors is translating into a discernible degradation of our members wellbeing.

Respondents were given the opportunity to elaborate on their experiences in free text responses:

"Feeling lonely and I have depression. Anxiety."

"I've been depressed at times. I was made redundant during this whole pandemic, so that contributed to my depression."

"I feel forgotten, I'm a working person and not been able to go out has been very hard, I get depressed very easily now and burst into tears for no reason and my mood changes very quickly."

"I'm a single Mum with sickle cell and I've struggled and still struggling with anxiety, panic attacks. I've had really sad days especially as my child is forced to shield with me and she has days when she really struggles because I can't take her to do normal things like she sees her friends do e.g. going for walks or bike rides with their families, most times I can't even go outside into the garden as other tenants in the house are using it too due to the good weather. She does understand but it still saddens me as what with both Sickle Cell disease and Covid I'm watching her grow up too fast."

"It has exacerbated my anxiety disorder, I have been more depressed and isolated. My parents have had to make adjustments in order to keep me safe. My mum had to stop working so that only one person was leaving the house so as not to increase the chance of exposure."

"As a carer my mental health was very challenged because the other household occupants had to make and adapt changes to our living space. i.e. having to keep distances from each other, not using the kitchen at the same time, not eating meals together, not socialising in the house together, not using the same utensils.... and the list goes on. This was a very lonely and depressing time for all, and at times resulted in minor arguments about who should be in the kitchen or bathroom. Emotionally, it was very difficult not to physically comfort the shielding person when finding it difficult to isolate in their own space for long periods of time."

A visual representation of the qualitative evidence given on the subject of mental health reveals a very despondent and dejected cohort:



- **16.8% of participants felt that their current living conditions hindered their ability to shield effectively and hence ensuring they were limiting their exposure to COVID-19.** This share of respondents lamented their living situation citing a plethora of reasons such as sharing with other non-shielding housemates, cramped and small living spaces, no access to green spaces - some likened the ordeal as to being incarcerated. This in conjunction with being unable to forego employment and having to risk their health in order to retain their jobs.

Respondents were given the opportunity to elaborate on their experiences in free text responses:

"Inadequate outside space for exercise and feeling enclosed for a family of 6 for many weeks."

"I'm a single mum and I need to work."

"I'm living in a flat and I have not got access to a garden to get fresh air or walk. I have got a history of low vitamin D and I'm worried that during this shielding, my levels might have gone low. I have informed the GP and they advised for me to book for blood test. I'm actually worried going out to the GP to take the test."

"I have not shielded in line with government advice as I have to work. Staying at home for 12 weeks was not for me. I was happy with the arrangement made at work with regards to social distancing, as a key worker public transport was less busy. So conditions were ok for me to continue working. My going out was however limited to work purposes."

"I live in a one bedroom flat with my 11 year old son and sharing a bed, not good!"

"I live in one bedroom with two of my kids. This makes it difficult to manage a daughter with sickle cell."

- **Moreover, disconcertingly 5.4% of respondents remarked that their living conditions weren't safe. It again cannot be stressed about the torrid circumstances people have found themselves in.** Shielding ineffectively has become a widespread problem due to the nature of housing, such as flatshares, in populous metropolitan hubs. We're told COVID-19 doesn't discriminate but structural inequalities have been amplified and brought to the fore. The COVID-19 pandemic is regressive in every way.

Respondents were given the opportunity to elaborate on their experiences in free text responses:

"The people I live with aren't able to work from home therefore they are not shielding and risk bringing the virus in with them."

"I get quite anxious that if anything happens to me, no one would know about it, for instance if i fall asleep and don't wake up, or slip whilst in the shower, if I have a crisis and I am unable to get out of bed then I will struggle. I ask my neighbours to knock my door every other day just to be sure I am ok."

"We managed by only allowing the shielding person to use the upstairs bathroom during the day, and we all use it at nights. The rest of the time other households use the downstairs shower and toilet. For using the kitchen, the shielding person was allowed to use the facilities before others, or when not in use by others."

- **35.6% of those who have had a crisis said they have not felt comfortable/safe enough to utilise A&E.** This concerning development means there has been evidence to suggest that service users have been delaying hospital visits and appointments out of fear of contracting the virus. There are safety measures and safety precautions that hospitals are taking such as hot and cold zones. It is of paramount importance that people do not delay presentation and seek treatment when necessary. It is the role of government to make this clear to the sickle cell population as over a third of respondents have had to endure a crisis without the appropriate pain management required.

Respondents were given the opportunity to elaborate on their experiences in free text responses:

"It's too high risk. I can't trust every other individual in A&E is obeying lockdown rules as strictly as I am."

"I just feel people who are asymptomatic might be in A&E and going there may expose me to the virus"

"Worried of catching Covid-19"

"Stayed home too fearful to go to hospital"

"My hospital had a lot of COVID-19 deaths. I was hoping I did not get sick during the lockdown. If I did, I would have tried to manage it at home and still avoided hospital."

"Went to A&E and they had no facilities for me there, I told them I was in shielding, but I was left in the waiting room all the other people."

"I know people that have gone to hospital, contracted covid-19 there, and died."

- **There has been an abundance of qualitative evidence to convey the overwhelming sense of anxiety over expected incomes, and apprehension on whether support will be guaranteed in the medium to long term. In addition, the delays in being able to access welfare assistance has been problematic.** There is palpable anxiety around members being able to stay afloat during the pandemic. A noticeable and worrying trend was the reliance on overdraft facilities and payday loans. As well as a large proportion of respondents informing us of job losses etc.

Respondents were given the opportunity to elaborate on their experiences in free text responses:

"Yes, my income has been affected, I can't work and can't be furloughed due to an umbrella company."

"Somewhat doing a few things from home so still getting my salary. My manager is quite understanding. I'm not too sure how much longer I would be able to continue not doing what I was hired to do with the same benefits. There's so much uncertainty. And as a non-citizen, I don't think I would be entitled to any government benefits."

"I've been told I'm not eligible since I'm a student but being home with my family, where my mother's income was drastically affected forced me to pay for things in the house"

My employer was going to put us on the furlough scheme, but they ended up going into administration and making us redundant. I applied for PIP around mid-March and I'm waiting for a response from the DWP. I'm currently on Universal Credits which is not enough to live on."

"My employer had managed for me to be able to work from home at the moment but not sure how long this will last."

"My partner income has been affected. We are now accessing benefits."

"My employer was going to put us on the furlough scheme, but they ended up going into administration and making us redundant. I applied for PIP around mid-March and I'm waiting for a response from the DWP. I'm currently on Universal Credit which is not enough to live on. I have not received sick pay."

"Contract terminated due to COVID19, not able to access any support. Not a registered carer therefore no assistance available."

- 69.5% of respondents felt there have been surprisingly some positive outcomes such as people being able to spend more time with family, spending less money and reducing their carbon footprint.

Respondents were given the opportunity to elaborate on their experiences in free text responses:

"I spent more time with family, made more gains in self-development, my body had the opportunity to rest."

"Getting into a productive morning routine, especially with exercising."

"I have spent precious time with my wife and kids which have been fortunate for us. So some good came out of this current nightmare."

"Increase skills digital transfer, and virtual meeting capabilities. Considerably reduced environmental footprint."

"Learning more about myself and taking care of my wellbeing. Spending quality family time, cooking new recipes, decorating, watching new movies, catching up with old friends loved ones! Although it was difficult to adjust at the beginning, I really made the most out of lockdown and I'm truly blessed to still be here."

"Not having to travel on the London Underground; not having to go into the office, and being with my family"

Policy Recommendations

See Appendix 1 for full data set & methodology

- **The SCTAPPG should write to NHS England to investigate the take-up of mental health services of those with sickle cell disease, and consider whether more can be done to encourage the utilisation of these services. Furthermore, from now on these mental health services should also be extended to primary caregivers of those with Sickle Cell Disease (SCD).** It is apparent we have already been sleepwalking into a mental health crisis, and although we recognise the commitment in the *'Five Year Forward View on Mental Health'* to expand access to IAPT services to people with long term health conditions, including those with sickle cell disease. It is abundantly clear that the psychological toll of the pandemic is translating into further impact on those who are clinically extremely vulnerable, and hence required to shield. Along with the everyday anxiety of having or caring for someone with SCD, the pandemic has particularly exacerbated the mental health impacts the SCD community face.
- **It should also be made clear to GPs and GP practices that those with sickle cell are afforded the option of an in-person appointment if they do not wish to do so virtually.** Too many members of our community have allayed their concerns that they are unable to communicate their condition effectively.
- **The SCTAPPG to write to the Parliamentary Under-Secretary of State for COVID Vaccine Deployment to ask for urgent clarification on the Joint Committee on Vaccination and Immunisation's (JCVI) advice on priority groups for COVID-19 vaccination. Specifically, clarity is needed on the eligibility of carers of clinically extremely vulnerable (CEV) individuals, and whether carers of sickle cell are also included in the fourth priority grouping.**
- **The SCTAPPG will write to the Department of Health and Social Care (DHSC) to request that the sickle cell community receive a bespoke letter of reassurance that it is safe for them to access healthcare services in their locality, and to not delay seeking treatment under any circumstance, in order to manage their condition. This new guidance should be drafted in consultation with the Sickle Cell Society and their medical/scientific advisors.** It is paramount that the government regains the trust of those living with sickle cell and this would be a first step in ensuring that this cohort feels comfortable to navigate their usual health pathways.

More than half of our community informed us that the COVID-19 had impacted their urgent access to healthcare services in their locality. Of those who hadn't been able to access all their healthcare services, more than a fifth reported that the stress had induced a Sickle Cell crisis. Our insight is that people with SCD are being offered these healthcare services but do not feel able to access them. Consequently, we recommend that this issue be addressed by augmented information and awareness, in a similar format to the government shielding letter.

- **The SCTAPPG to write to the Ministry of Housing, Communities and Local Government to outline the responsibility the department has to ensure the safety of those who are deemed clinically vulnerable, such as those with sickle cell disease. It is incumbent on all housing associations to be instructed to contact those with SCD to discover whether their current living condition is hindering their ability to shield. If so, they and their family should be given an option to relocate to housing which enables them to shield effectively.** Many

respondents made clear though their appetite to follow government guidance wasn't in doubt; they weren't being able to follow it due to their living conditions.

Conclusion

Intrinsically COVID-19 does not discriminate, pandemics don't choose their victims and a virus does not select its host. But what is safe to say is that in a society where structural inequalities exist whether that be by socio-economic background, race, gender, disability – COVID-19 does discriminate. The likelihood of contracting the virus increases or decreases dependent on these aforementioned variables. And though it has not been proved beyond doubt that having sickle cell decreases your chance of survival, your race and socio-economic background have been proven to increase your likelihood of contracting the virus. If you take one of our members who is BAME, has sickle cell and from a lower socio-economic background, they are more likely to suffer from COVID-19. Consequently, COVID-19 does discriminate, it has served to exacerbate and amplify the health inequalities that already exist.

The demography of our service users must not be ignored in the role it is playing, and we have sought to view their struggles through this lens. In the COVID-19 Marmot Review he has stated BAME groups are experiencing higher rates of mortality from COVID-19. This is related to their disproportionate experience of high-risk living and working conditions. He attributes this in part to longstanding impacts of discrimination and exclusion associated with systemic racism. Lessons need to be learned and decisive, meaningful and swift action needs to begin to ameliorate these inequalities.

COVID-19 is one more obstacle to navigate for those living with sickle cell and their primary care givers. Moreover, the barriers to entry that already exist have only been strengthened and intensified during this pandemic. Therefore, it is incumbent on the government to act on the substantial evidence which shows our members are fearful at losing their lives, their loved ones or in some cases both. The SCTAPPG has sought to provide practical policy recommendations which could make a real tangible difference to the safety and wellbeing of our members.

Appendix 1

Survey Process and Outcome

Methodology

In order to determine the multi-faceted impact that the COVID-19 pandemic has had on the sickle cell community, the SCTAPPG commissioned a survey in which aimed to capture the experiences of living/caring for someone with sickle cell disorder in the COVID-19 pandemic. Amongst a host of objective, it was key to use this data to determine whether those living/caring for someone with sickle cell disorder are receiving all the information required, and whether the government guidance is suitable for their circumstances. The survey was launched on 28th May 2020, and then distributed to sickle cell service users through the Sickle Cell Society membership. In order to increase the reliability of results the survey was distributed widely disseminated throughout patient groups and clinical networks to garner as many responses as possible - the use of convenience sampling made this possible. We had considerable participation with 186 self-selected respondents, primarily through accessing the networks of patient groups and encouraging them to share the questionnaire.

The survey and report are authored by Adam Lloyd.

The data collected was secure, protected, and covered by the privacy statement outlined on the Sickle Cell Society website, which adheres to the latest GDPR regulations. All respondents' information is confidential and hence they will not be made identifiable in the analysis that follows.

Results of Survey

Participant Population

Pie chart 1, 2 and 3 below illustrates the composition of the participants that made up the data set. It is apparent that approximately 70% of respondent themselves have sickle cell disease with the remaining cohort being a family member/ caregiver which provides a wide-ranging insight into what is a tapestry of experiences. The age of respondents is equally as diverse with participant from all manner of age groups, it is not surprising to see less uptake from those 70+ due to technical obstacles as well as 18-24 bracket who may well be not be as engaged with the Sickle Cell Society's work along with their healthcare needs being still administered by their parents/caregivers.

The respondents as discernible from the evidence are regionally diverse. The data size allows us to be sure the sample size is adequately representative of the national picture in England. Unsurprisingly a large section of the cohort was based in London, this was presumably due to the high prevalence of those with sickle cell in the capital. There was also a considerable from the Midlands and the North West where there is higher prevalence. There was representation from all regions of the United Kingdom, with the devolved nations making 3.2% of the data set. We presume that the data would look much bleaker if we'd had engagement from rural areas where the prevalence of SCD would be much lower due to the smaller minority ethnic population in those areas.

Chart 1 – Who is completing this survey?

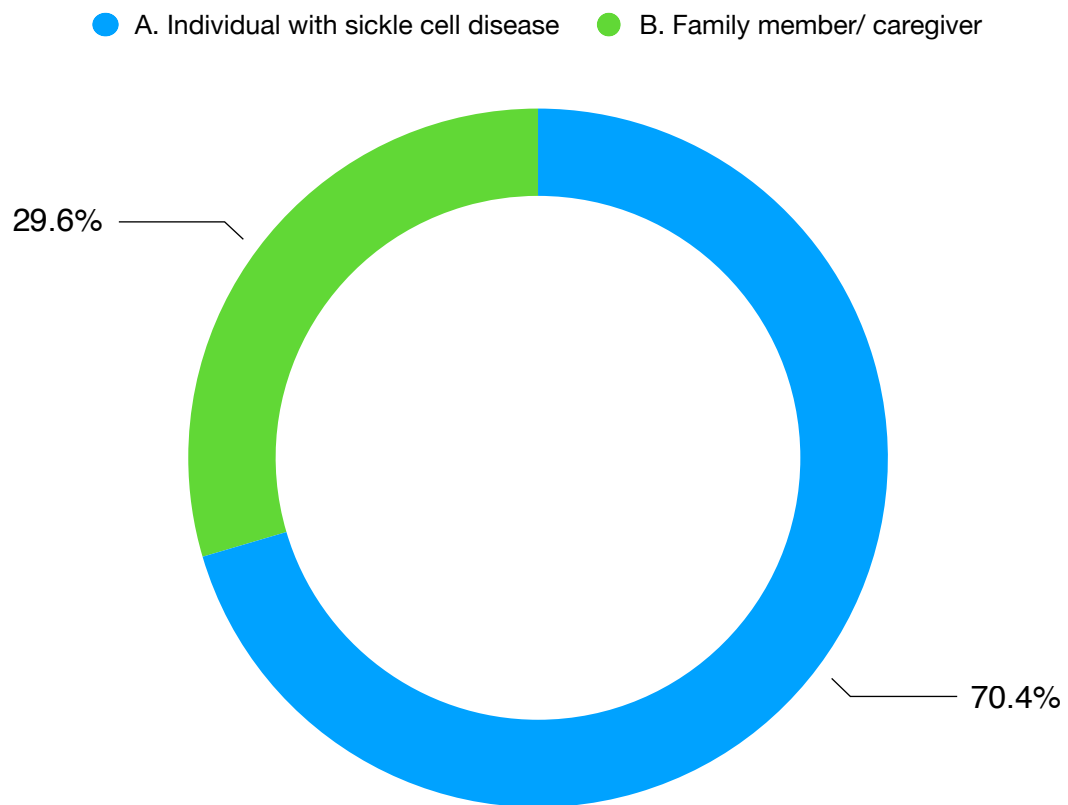


Chart 2 – Age of participants

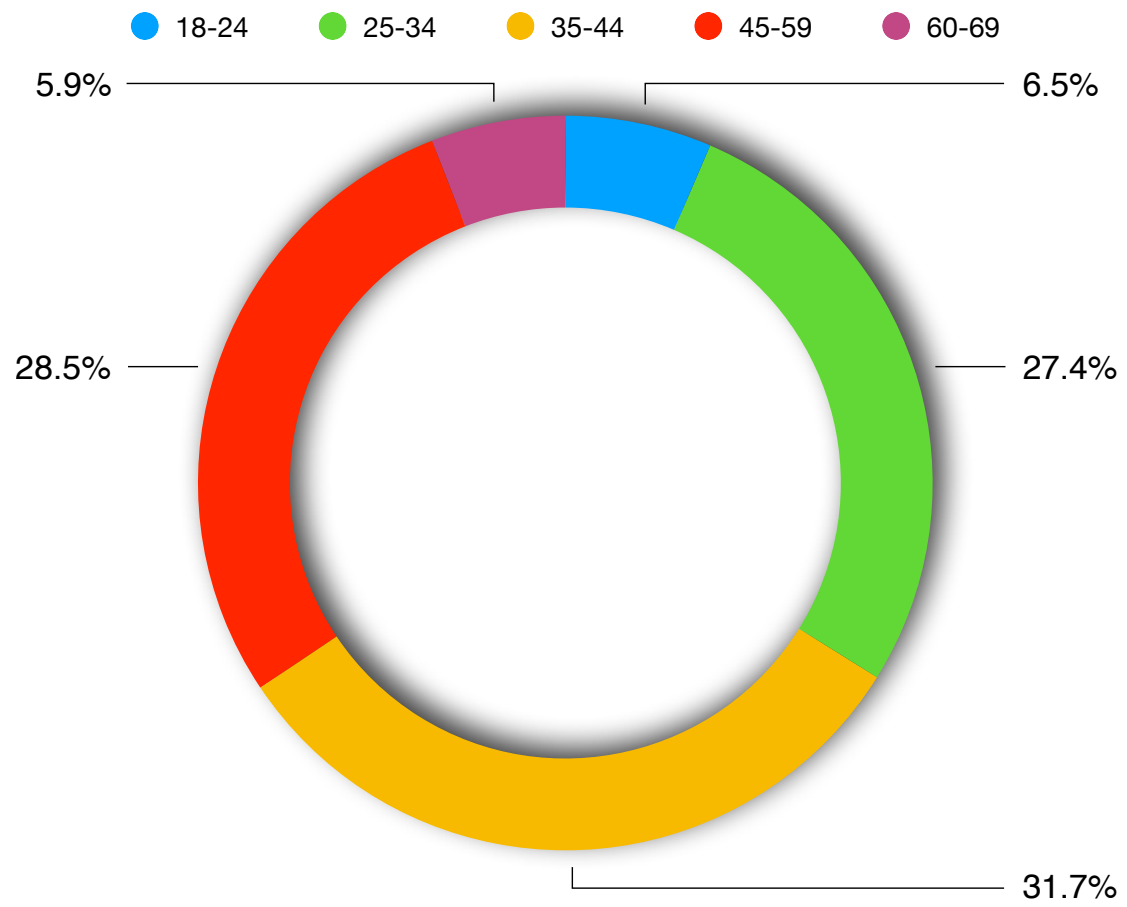


Chart 3 – What region of the UK are participants from?

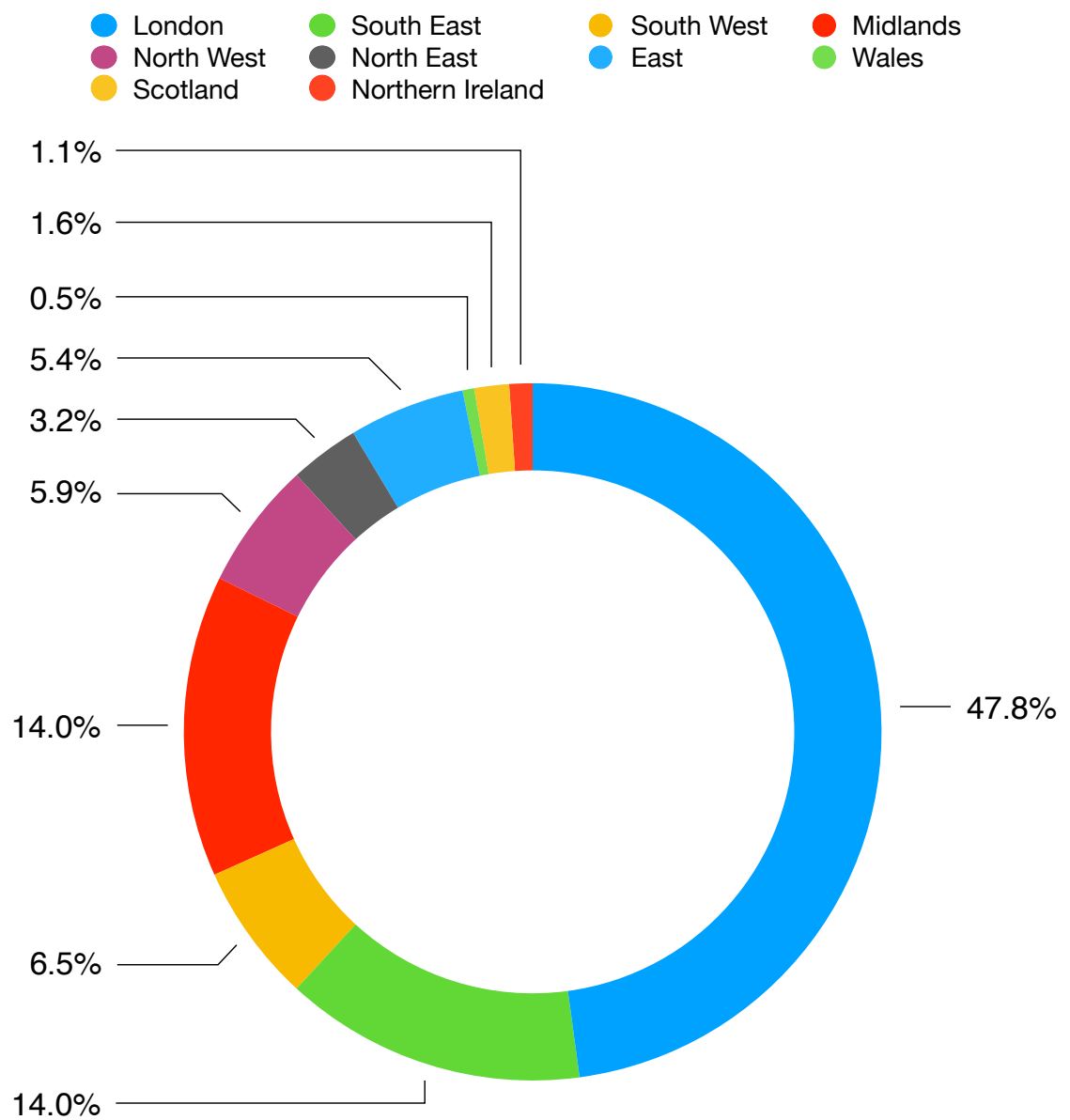


Chart 4 - Has COVID-19 affected your access to healthcare services in your locality? Yes/No (Chemist, outpatient appointment, regular transfusions, GP Service Provision etc.)

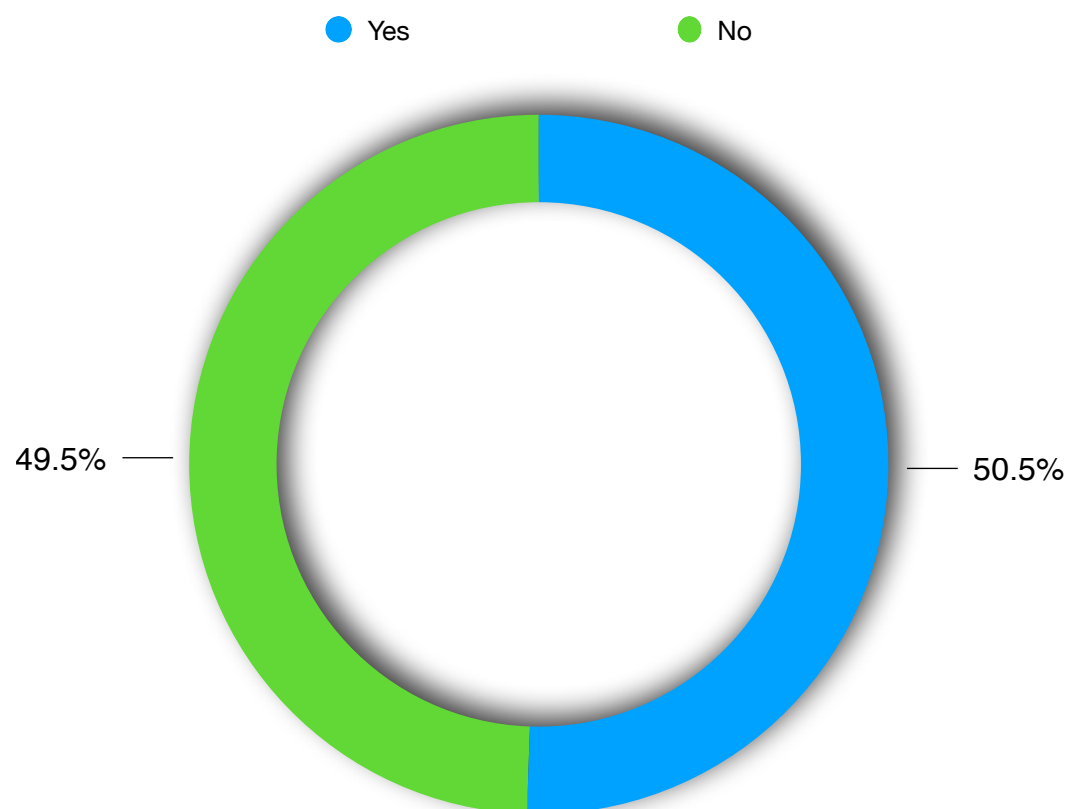


Chart 4 reveals a chilling fact that just over half of all respondents have revealed that their normal health pathways were disrupted by the pandemic. This failure to access healthcare services will most likely be in direct contradiction of doctors' orders who have clear advice on the most effective treatments and advice on healthcare needs. There is a general consensus that cancellations of GP/outpatient appointments/annual consultations/planned surgeries/planned routine check-ups/scans is a prevailing issue along with having to conduct appointment over the phone and not in person are playing a negative role in not only service users physical health but also their mental health. The inability to be able communicate effectively one's condition has left service users feeling helpless to improve their condition. Furthermore, a reliance on support networks to carry out visits to the chemists/pharmacies puts those without those very networks at risk of failing to adhere to medical advice.

In free text responses respondents were offered the opportunity to elaborate:

"Due to shielding, you can only talk to the GP on phone, you can't even go to the chemist. You need to ask someone to do that for you. Consultant routine appointments have been rescheduled."

"Unable to access chemist to collect prescriptions, I was forced to rely on volunteers to collect."

"In regards to the chemist, I have not been able to go and collect pain relief for my child."

"It has been harder to get prescriptions and also getting medication delivered on time to manage my sickle cell. I wasn't able to have regular blood tests to help monitor my condition."

"There was a delay of 3-4 months where I was not able to receive my 5-year pneumovax injection, nor could I see my Haematology team"

"I wasn't able to attend my hospital appointment due to the pandemic/fear of catching COVID-19."

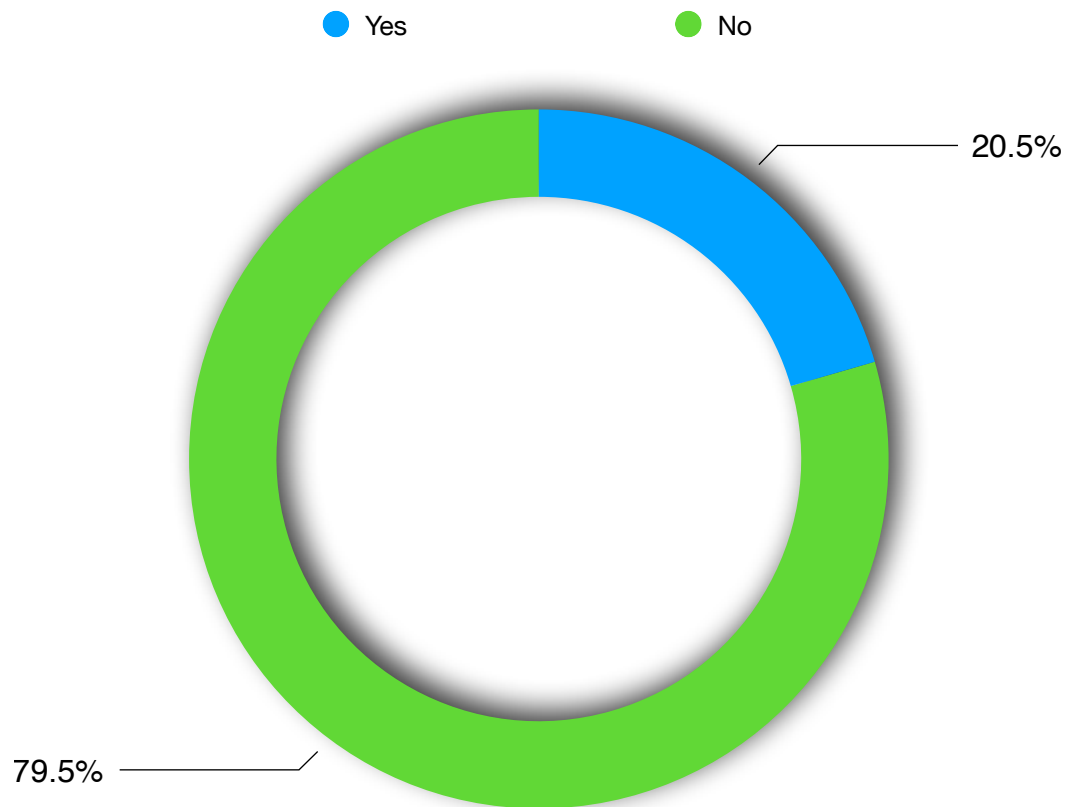
"I can't receive Blood Exchanges because I don't have access to theatres for a main line insertion."

"GP refused face to face appointment, I ended up in hospital with severe pneumonia because they didn't listen to my chest."

"I find it harder to access non-sickle related medical support as it takes So much longer due to back log etc e.g. waiting for surgery to remove a pre-cancerous lesion which has increased my level of anxiety as I haven't heard back and not sure how to chase it up and that's just one example."

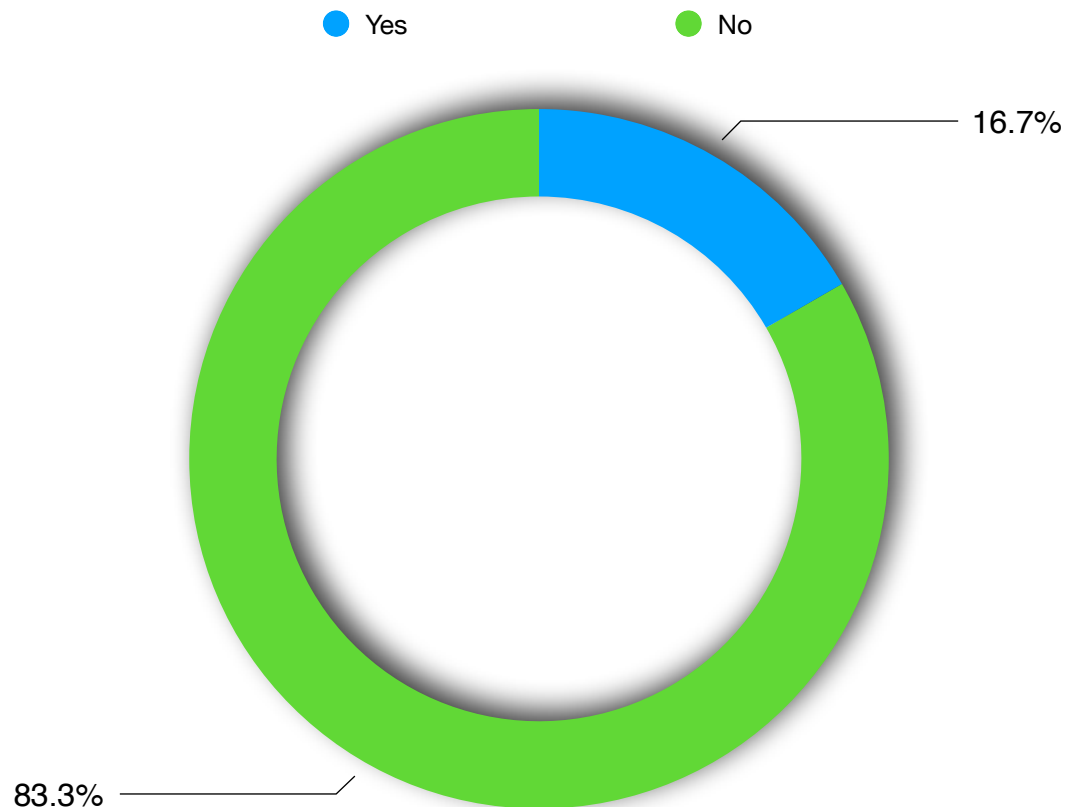
"Trying to be seen has been such a problem, especially when I had an acute chest syndrome flare up. My last crisis I was sent home because I had a temperature and chest pain even when I explained I have a negative covid result."

Chart 4a - And if you have not been able to access healthcare has this brought on a crisis



The pie chart depicts a very sizable 20.5% of respondents who said the failure to access the necessary healthcare had brought on a crisis.

Chart 5 - Have you or anyone you know living with SCD had COVID-19?



16.7% of respondents' cases of COVID-19 were documented by participants, they either knew people who had recovered or passed from coronavirus. There were some harrowing anecdotes of personal tragedies along with disillusion with respondents complaining about being sent home prematurely. That having SCD sometimes they felt hindered them getting treatment as they were vulnerable to transmission.

In free text responses respondents were offered the opportunity to elaborate:

"A five year old child with sickle cell anaemia passed away. The family was known to a sickle cell support group that I belong to. This loss made me and other care givers very anxious and had a negative impact on my mental health. The trauma and the bereavement caused me to experience panic attack due to anxiety around my children having sickle cell anaemia. The person recovered thankfully! They were initially sent home after going to hospital, but when things got worse at home they called for an ambulance which took them to hospital. They recovered in hospital but ended up with very bad lung scarring."

"I tested positive for corona virus. And recovered"

"I knew of a fellow sickler who contracted Covid through her care workers, last I spoke with her before doing this survey, she was still in hospital but on the road to recovery."

"I know 2 young people living with SCD has Covid-19 and recovered"

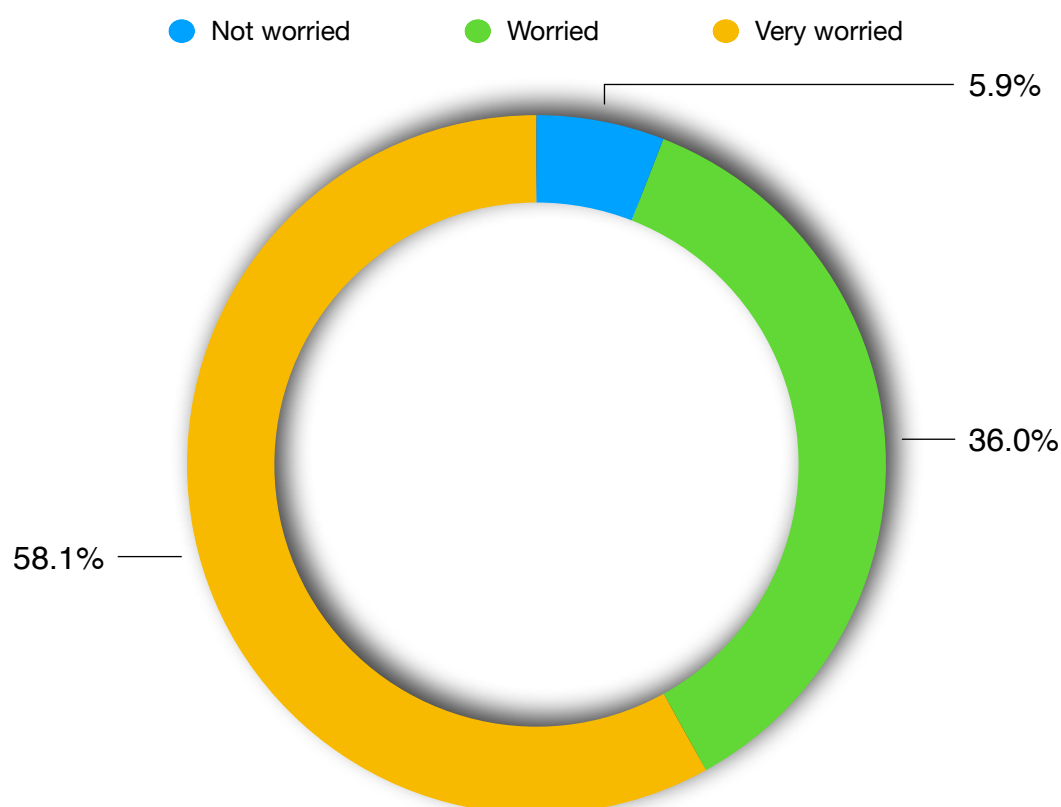
"I had COVID-19 and was seriously ill. Was admitted to hospital and spent a few days there. Did not need to go to ITU thankfully. But it took me about 5 weeks to get better physically. I am still dealing with the emotional scars and I'm sure they will never disappear."

"Friend with SCD got sent home from hospital with COVID and almost died. Her teen son called 999 just in time. She still hasn't fully recovered and its frightened fellow sufferers"

"My new born and I had covid it was a traumatic for me but we pulled through."

"A patient I knew died from COVID-19"

Chart 6 - To what extent, if at all, are you worried about being more at risk of the consequences of COVID-19 because of your sickle cell?



Understandably, a staggering 94.1% of respondents felt either worried or very worried about the risk of the health consequences from COVID-19.

In free text responses respondents were offered the opportunity to elaborate:

"As stated above, I heard about a children with sickle cell anaemia that passed away from Covid 19 and this increased my anxiety and caused a lot of worry."

"I had pneumonia last year and other severe crisis due to infections so spent a lot of time in hospital. I still have not completely mentally recovered from this so am very anxious about getting more ill and being severely ill from COVID-19."

"Not so much worried but cautious. Because I don't have a spleen so my immune system is very low."

"I fear my partner's chances of surviving COVID-19 are low."

"I'm made to understand that COVID-19 affects both the immune system and respiratory organs. My lungs have diminished lung function capacity and a pretty low immune system."

"Not only does my husband have Sickle-Cell SS he has Beta Thalassaemia, G6pd Deficiency, myocarditis. We know would be miracle if survives."

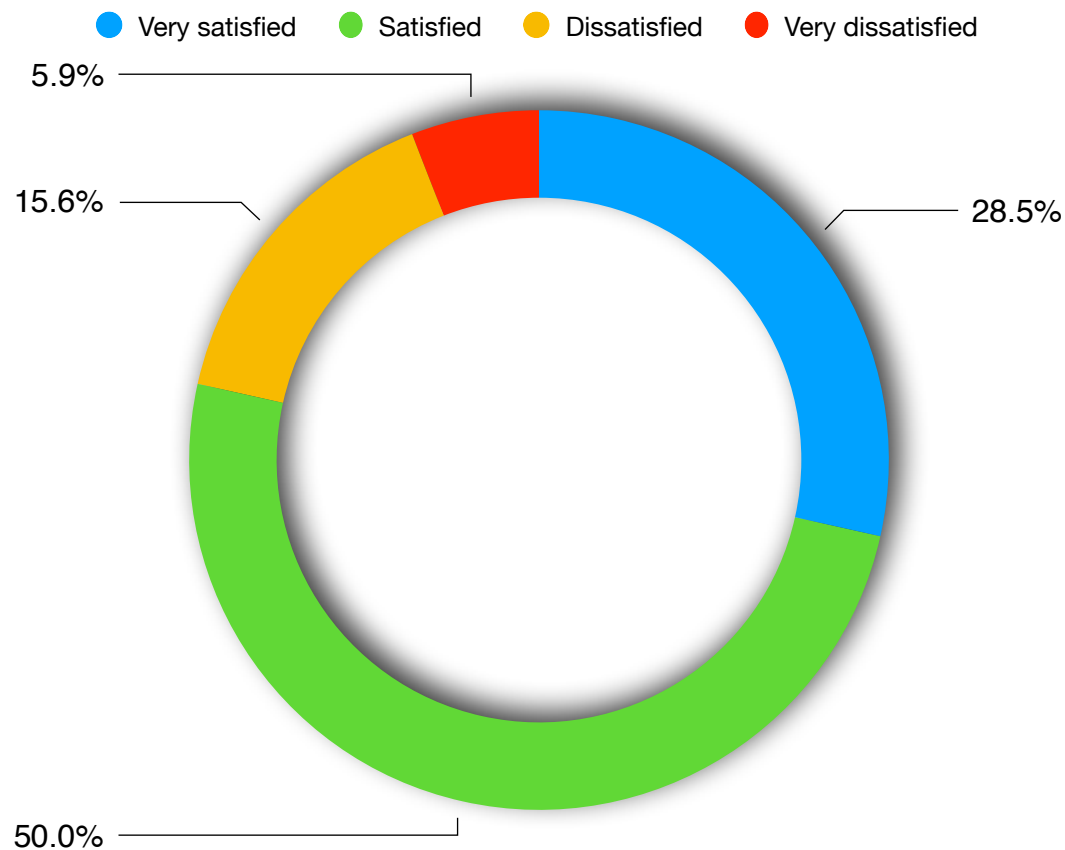
"I'm worried because if I was to get covid, would I survive? My immune system is so weak and it just scares me because I don't know if my body would be able to handle it."

"I don't know what to expect or how my body will deal with the disease. I am being very cautious and shielding but with isolation/lockdown/quarantine coming to an end, I find myself stressed because I'm not sure how to protect myself from the disease."

"So many factors contribute to my Covid anxieties e.g. my job, my health (immune system and respiratory system not up to par), my child (the possibility of her bringing it home to me from school) etc."

"I fear if I catch it, it could kill me."

Chart 7 - How satisfied or dissatisfied are you with the information available to you about COVID-19, sickle cell and sickle cell trait? E.g. were you aware individuals with sickle cell were classed as vulnerable?



Though it is somewhat reassuring that the bulk of participants at 88.5% felt either satisfied or very satisfied with the current information that had been disseminated. It must be of paramount concern that all respondents are and feel fully informed about how they must conduct themselves during the pandemic.

In free text responses respondents were offered the opportunity to elaborate:

"There has been limited information from the government since the lockdown was relaxed about how people classified as vulnerable such as people living with sickle cell anaemia should keep themselves safe. Messages are confusing around sending children to school or returning to work. There hasn't been clear messages about how to protect the children living with sickle cell anaemia condition."

"The government, my GP, and sickle clinic failed to contact me. I had to call several times to all three to ask why I was not informed in any form. All was unsure. I was contacted on 24th April weeks into lockdown from my GP to apologise that I had not been told or highlighted to the NHS as vulnerable. Up to date my parents of the same address and GP who are both sickle trait, diabetic and over 70 have not been contacted!"

"The information is very generic."

"Not clear guidelines out there to guide patient. Especially employers wanting us to return back to work and it will be useful to have something out there to support us in what to say or expectations for employers to put in place before starting work."

"Heath care professionals have not provided any information about the risks, only that you should self-isolate! No solutions, no data, no specifics; just self-isolate in limbo."

8a. Did you get any information from the Sickle Cell Society website?

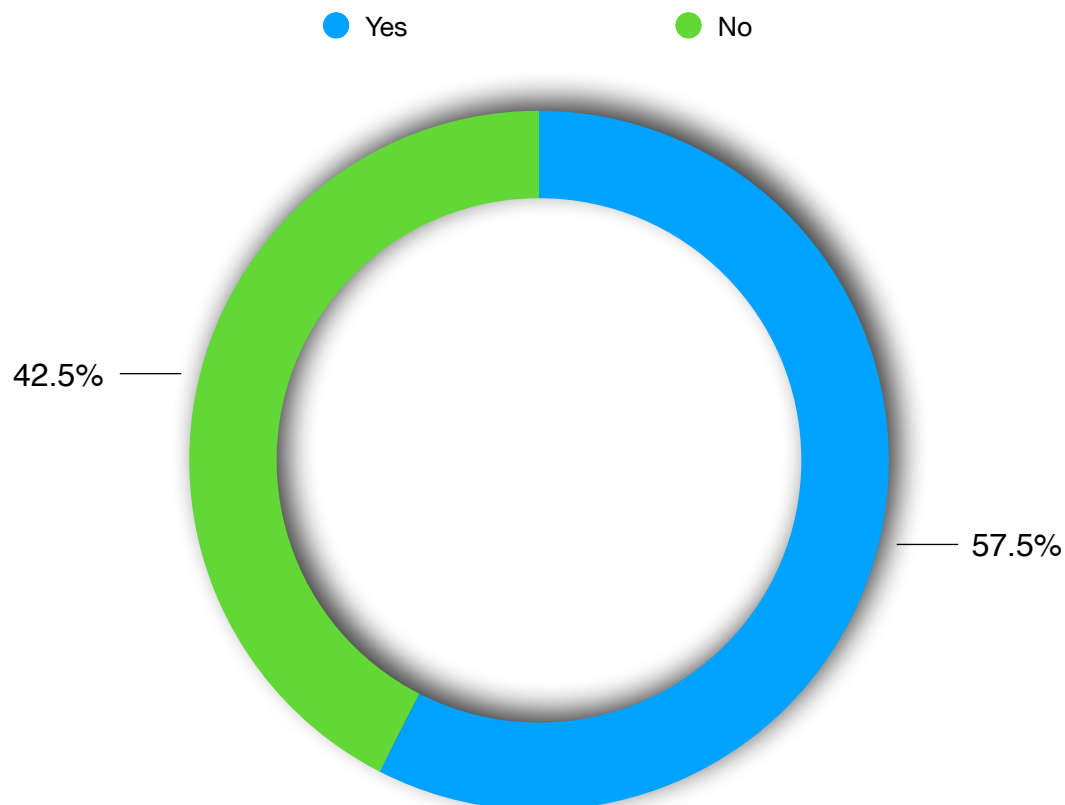


Chart 8a. shows that over half (57%) accessed information from the sickle cell society which has the most up to date guidance on its website.

8b. In regards to the content on the Sickle Cell Society website, were you?

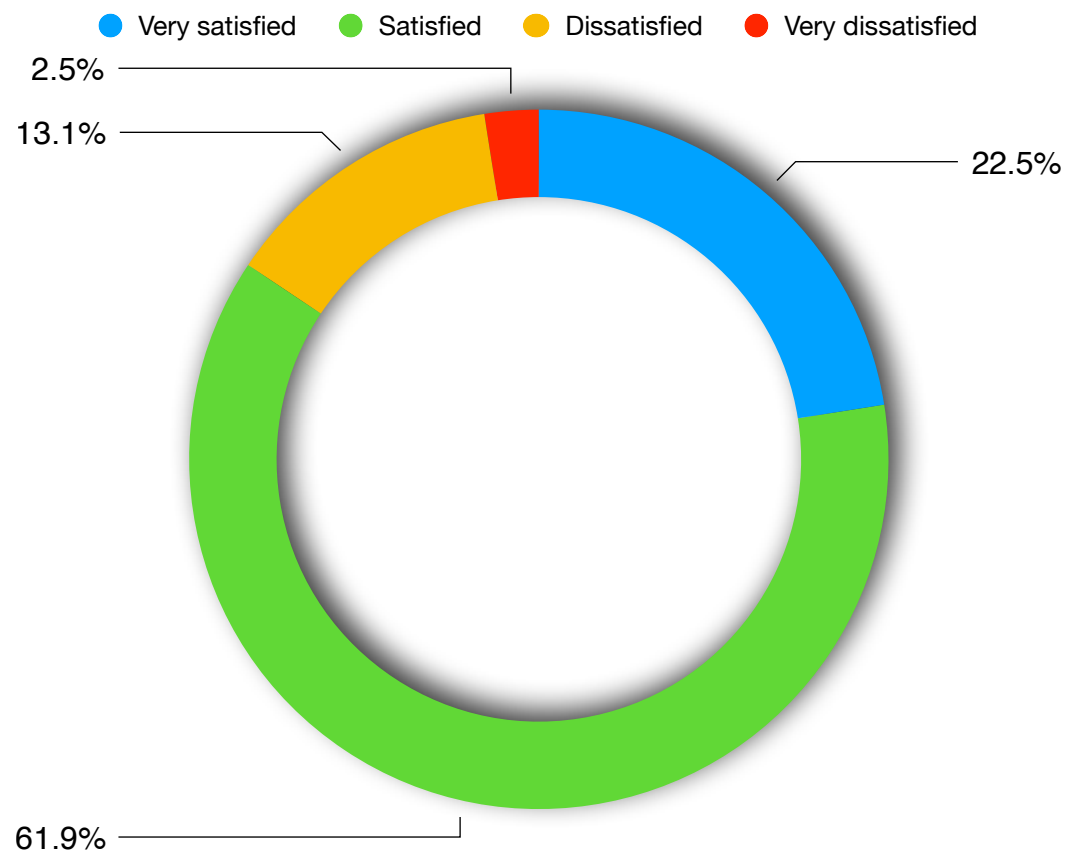


Chart 8b. illustrates the content of which was well received with a very sizable 88.4% being satisfied or very satisfied with the advice and support outlined on its website.

In free text responses respondents were offered the opportunity to elaborate:

"Very good guidelines."

"The sickle cell society has provided lots of information and online seminars during this pandemic. Information very clear and easy to follow."

"It has up to date information and very informative."

"It was clear, detailed, informative well set out guidance and advice. Plus, it is signposted and has useful other associated information."

"It was very detailed and specific. Accessible because I follow them on Instagram and Facebook."

Chart 9 - Did you receive a letter or text advising you to shield as one of the vulnerable groups who was instructed by the government?

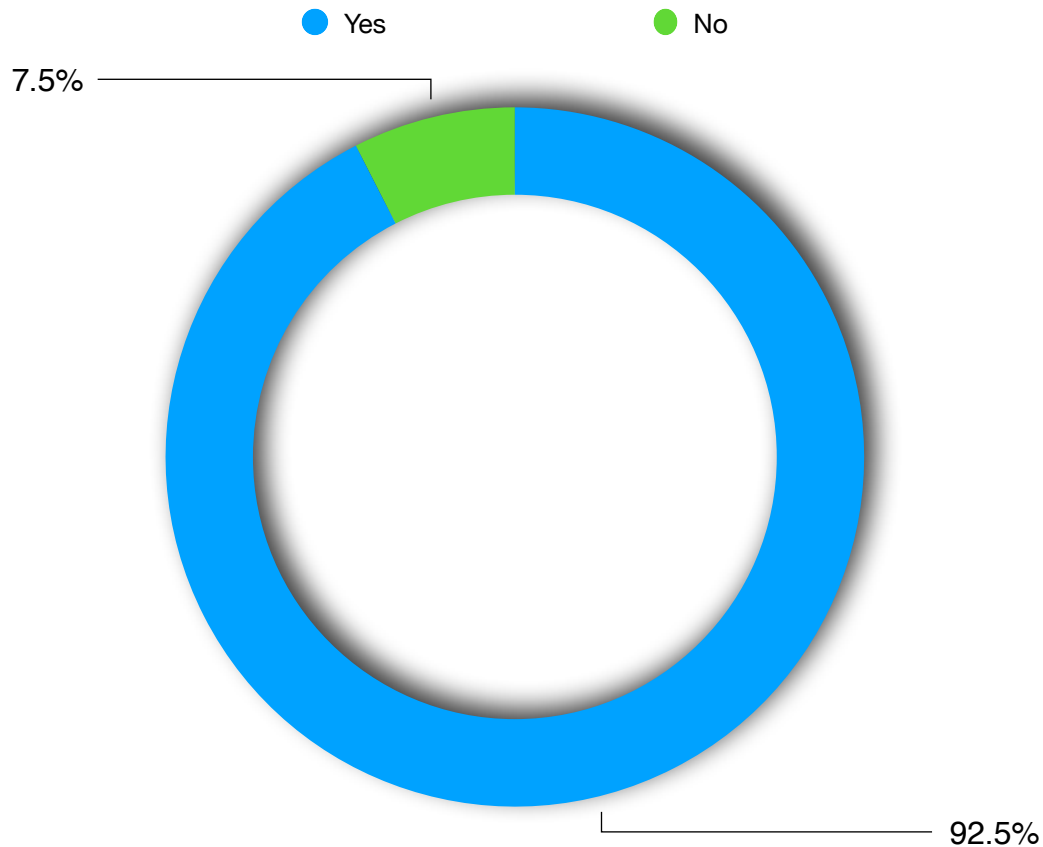


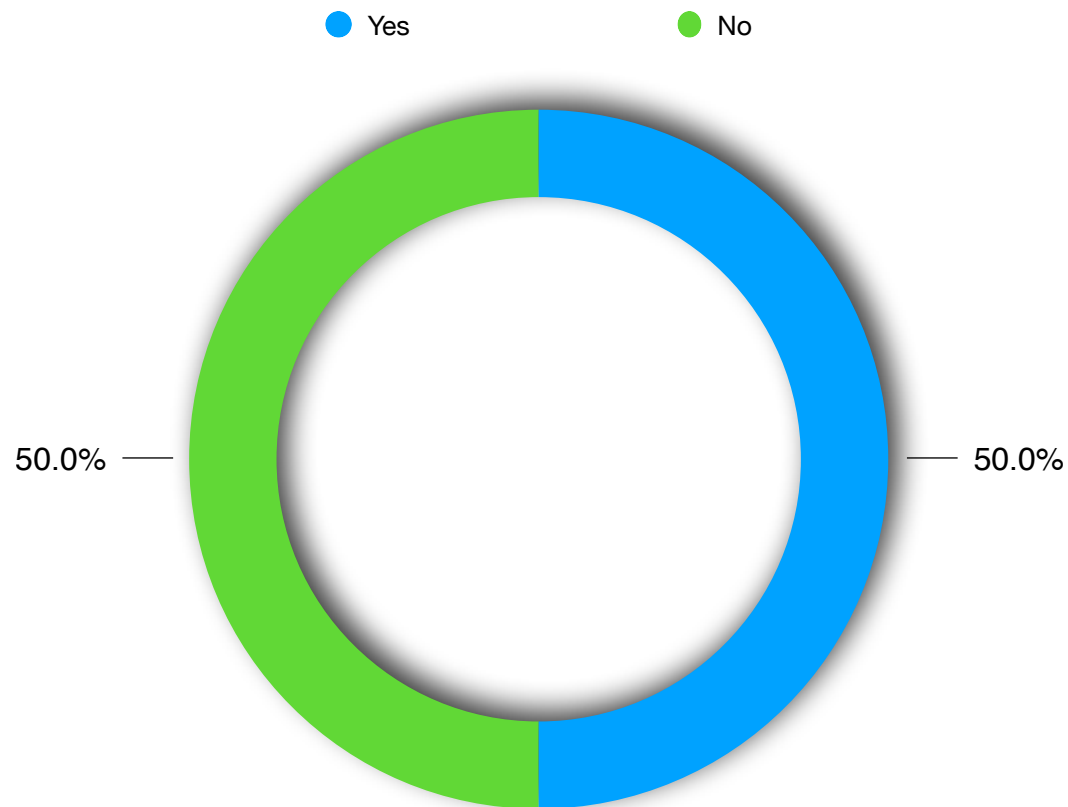
Chart 9 shows a concerning percentage of services users who were not contacted by the government via text or letter. It is integral that those who are required to shield are reached to inform them of the necessary steps to take. Though the majority of respondents did, 7.5% is just too much to allow. Most respondents received a text or letter in Late March to early April.

In free text responses respondents were offered the opportunity to elaborate:

"I did not receive one initially, it took three weeks of questioning my GP on why I did not receive a letter. With Sickle cell, a non-functioning spleen and chemo, I was missed from the list. Apparently my local surgery had the wrong the wrong code next to my name and they had classified me as a sickle cell trait instead of sickle cell disease. It took three weeks to rectify and then I received the text and help available."

"Four weeks after the government made the announcement."

Chart 10 - If you have not received a letter or text advising you to shield, have you been told by another source that you should be shielding?



A half and half split on those who were informed by another source as well as the government with those who did receiving personal phone calls from their GP's, local hospitals and local authorities. This evidence shows that a joined up multi agency approach is effective if employed and it does become apparent that the remaining 50% did not have the same level of engagement.

Chart 11 - Has social distancing and self-isolation affected the mental health of:

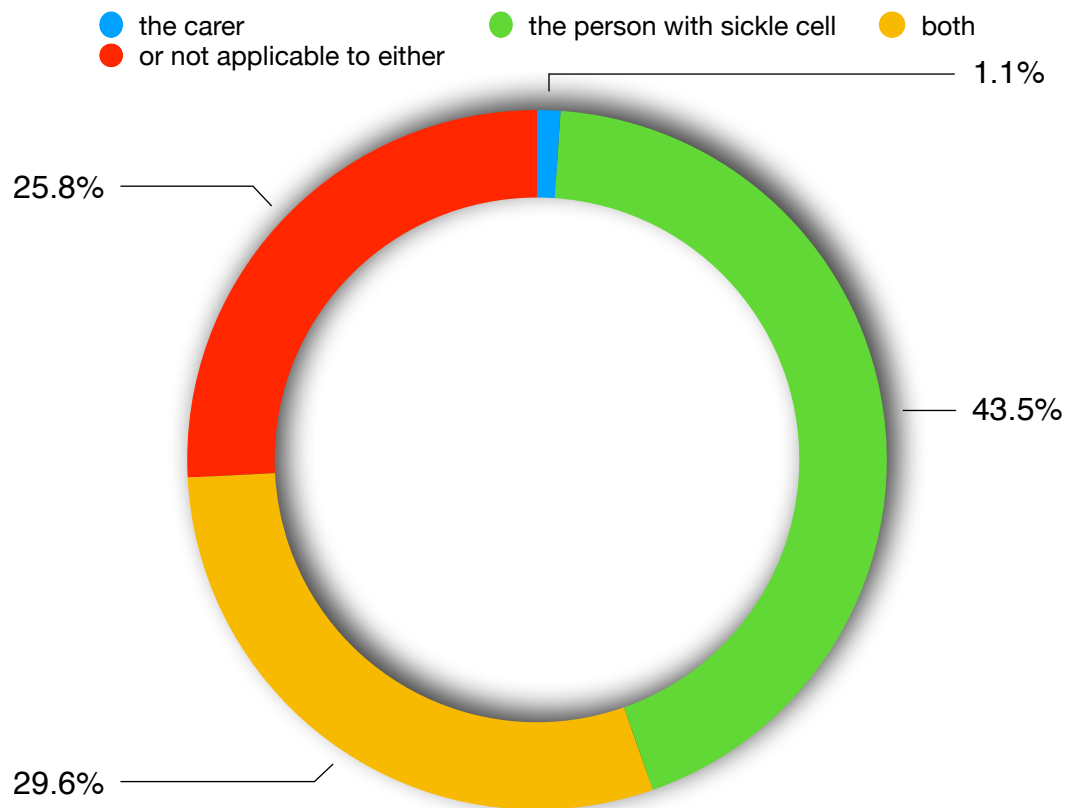


Chart 11 shows almost three quarters of people (73.7%) are experiencing an impact on their mental health. In very striking testimony it is abundantly clear that the psychological toll the pandemic is having on those who are required to shield is enormous and was underestimated. Along with the everyday anxiety of having or caring for someone with the condition, this pandemic has exerted an incredible upsurge of trauma in the SCD community. From the confusion around SCT guidance, the loneliness, and uncertainty about when the panic will be over. This cocktail of damaging factors is translating into a discernible degradation of our members wellbeing.

In free text responses respondents were offered the opportunity to elaborate:

"I have experienced panic attacks since the Covid 19 pandemic started. My daughter has also experienced some anxiety about the pandemic due to the fear of catching the disease and possible complications from the disease."

"Feeling lonely and depression. Anxiety."

"I've been depressed at times. I was made redundant during this whole pandemic, so that contributed to my depression."

"I feel forgotten, I'm a working person and not been able to go out has been very hard, I get depressed very easily now and burst into tears for no reason and my mood changes very quickly."

"I'm a single Mum with Sickle Cell and I've struggled and still struggling with anxiety, panic attacks. I've had really sad days especially as my child is forced to shield with me and she has days when she really struggles because I can't take her to do normal things like she sees her friends do e.g. going for walks or bike rides with their families, most times I can't even go outside into the garden as other tenants in the house are using it too due to the good weather. She does understand but it still saddens me as what with both Sickle Cell disease and Covid I'm watching her grow up too fast."

"It has exacerbated my anxiety disorder, I have been more depressed and isolated. My parents have had to make adjustments in order to keep me safe. My mum had to stop working so that only one person was leaving the house so as not to increase the chance of exposure"

"As a carer, my mental health was very challenged because the other household occupants had to make and adapt changes to our living space. i.e. having to keep distances from each other, not using the kitchen at the same time, not eating meals together, not socialising in the house together, not using the same utensils.... and the list goes on. This was a very lonely and depressing time for all, and at times resulted in minor arguments about who should be in the kitchen or bathroom. Emotionally, it was very difficult not to physically comfort the shielding person when finding it difficult to isolate in their own space for long periods of time."

"I'm in a much better place and so are my loved ones but as we all know, covid-19 has been a challenge for us all. Having to shield for 12 whole weeks was not easy (mentally and physically). I sometimes felt guilty having my mum help me out with shopping and collecting my prescriptions. I felt so powerless. Now that lockdown has eased, I have been able to go out and meet a few family and friends. I'm trying to adjust to the new normal by being cautious, mainly wearing my mask and avoiding mixing with large groups of people. I find that I have to turn down a lot more invitations than usual, as I still don't feel comfortable in certain environments at the moment. Not everyone has the same attitude towards this and sometimes I feel like I'm not understood. I've learnt that everyone has different circumstances and as someone living with sickle cell disease, I have to do what's right for me."

Chart 12- Is your current living condition helping you shield?

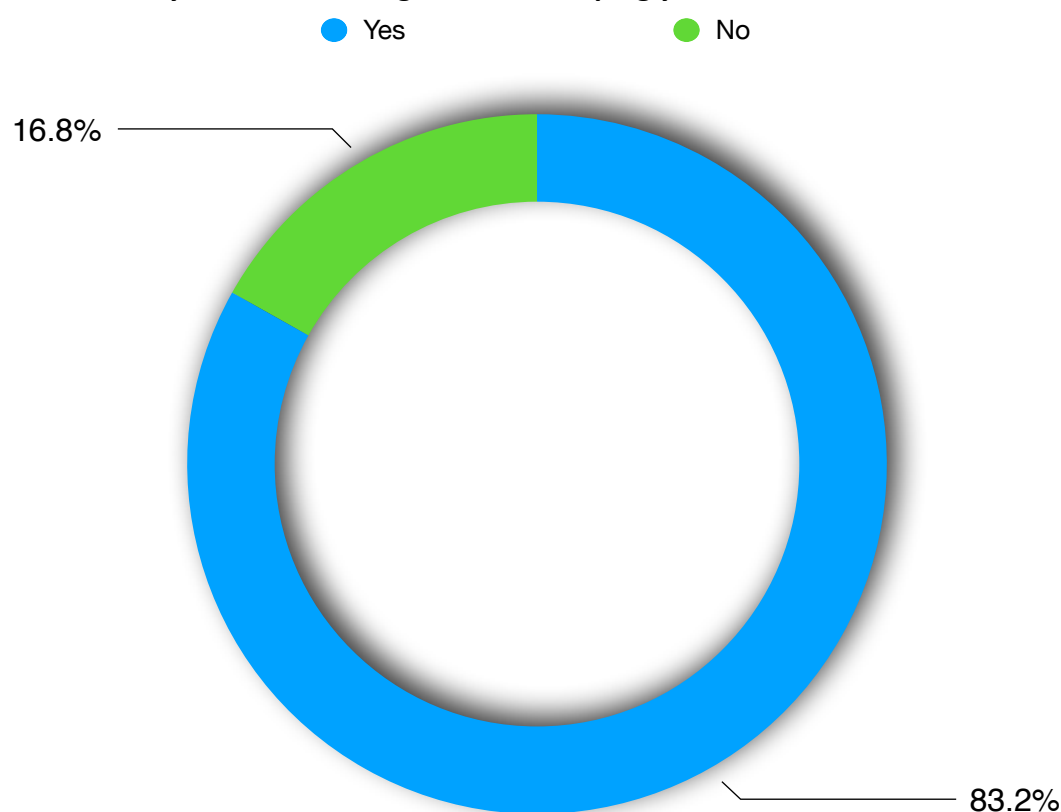


Chart 12 has 83.2% responding that their current living conditions enabled them to shield effectively and ensuring they were limiting their exposure to COVID-19. 16.8% of participants felt that their current living conditioned hindered their ability to shield effectively and hence ensuring there were limiting their exposure to COVID-19. This share of respondents lamented their living situation citing a plethora of reasons such as sharing with other non-shielding housemates, cramped and small living spaces, no access to green spaces along with being unable to forego employment and having to risk their health in order to retain their jobs. Some likened the ordeal as to being incarcerated.

In free text responses respondents were offered the opportunity to elaborate:

"Inadequate outside space for exercise and feeling enclosed for a family of 6 for many weeks."

"I'm a single mum and I need to work."

"I'm living in a flat and I have not got access to a garden to get fresh air or walk. I have got a history of low vitamin D and I'm worried that during this shielding, my levels might have gone low. I have informed the GP and they advised for me to book for blood test. I'm actually worried going out to the GP to take the test."

"I have not shielded in line with government advice as I have to work. Staying at home for 12 weeks was not for me. I was happy with the arrangement made at work with regards to social distancing, as a key worker public transport was less busy. So conditions were ok for me to continue working. My going out was however limited to work purposes."

"Live in a one bedroom flat with my 11 year old son and sharing a bed, not good."

"I live in one bedroom with two of my kids. This make it difficult to manage daughter with sickle cell."

Chart 13 - Is your current living condition helping you shield?

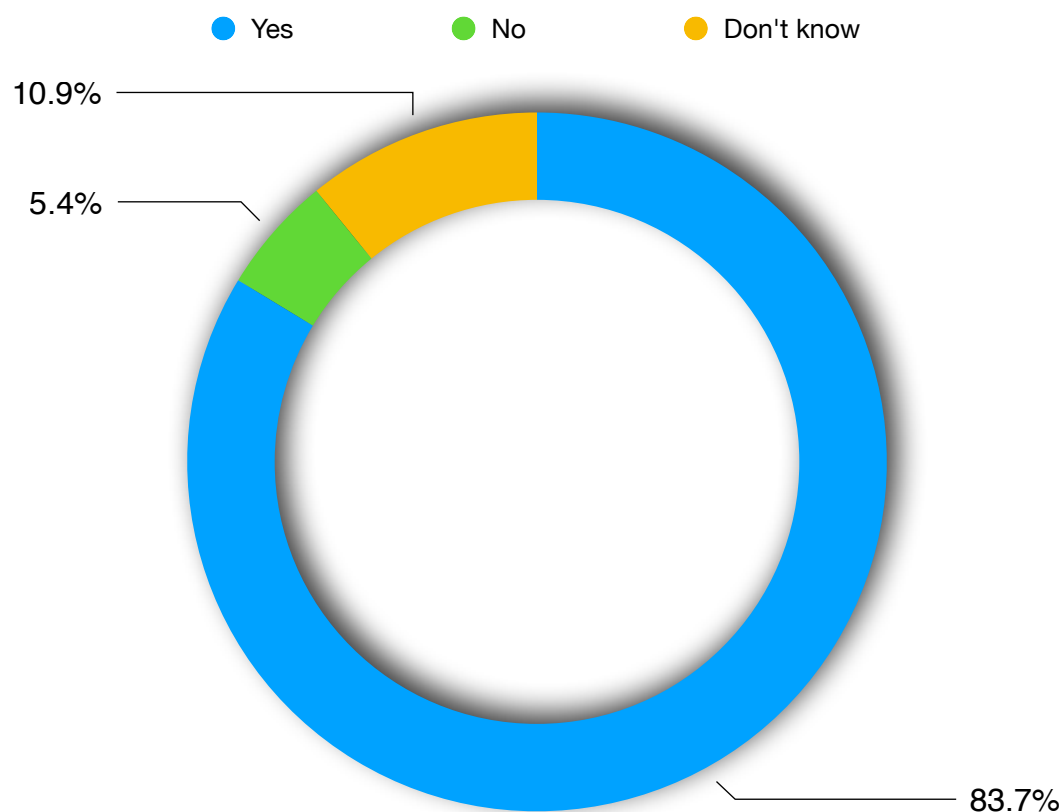


Chart 13 shows 5.4% of respondents remarked that their living conditions weren't safe. It again cannot be stressed about the torrid circumstances people have found themselves in. From the nature of the housing meaning flat shares are typical in metropolitan hubs it has translated into a gaping problem of those not being able to shield effectively. COVID-19 doesn't discriminate but these structural injustices have amplified and brought to the fore those who face hardship whether through their disorder, income or race that these have a significant impact on you.

In free text responses respondents were offered the opportunity to elaborate:

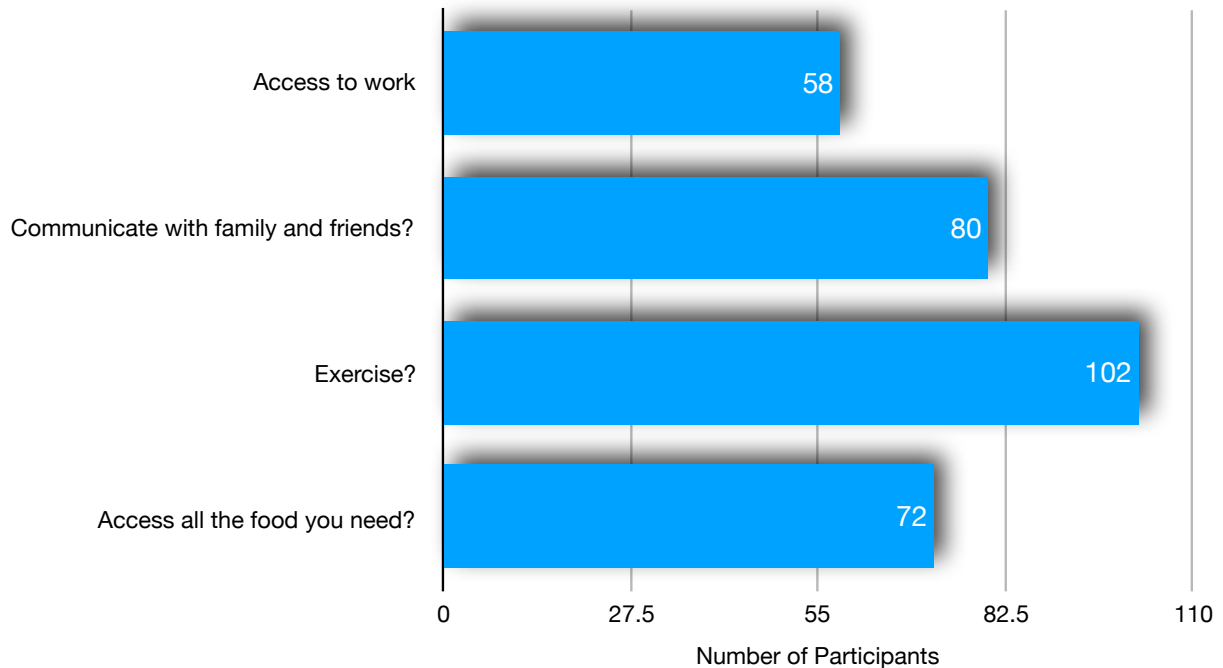
"The people I live with aren't able to work from home therefore they are not shielding and risk bringing the virus in with them."

"I get quite anxious that if anything happens to me, no one would know about it, for instance if I fall asleep and don't wake up, or slip whilst in the shower. If i have a crisis and I am unable to get out of bed then i will struggle, I ask my neighbours to knock my door every other day just to be sure I am ok."

"We managed by only allowing the shielding person to use the upstairs bathroom during the day, and we all use it at nights. The rest of the time other households use the downstairs shower and toilet. For using the kitchen, the shielding person was allowed to use the facilities before others, or when not in use by others."

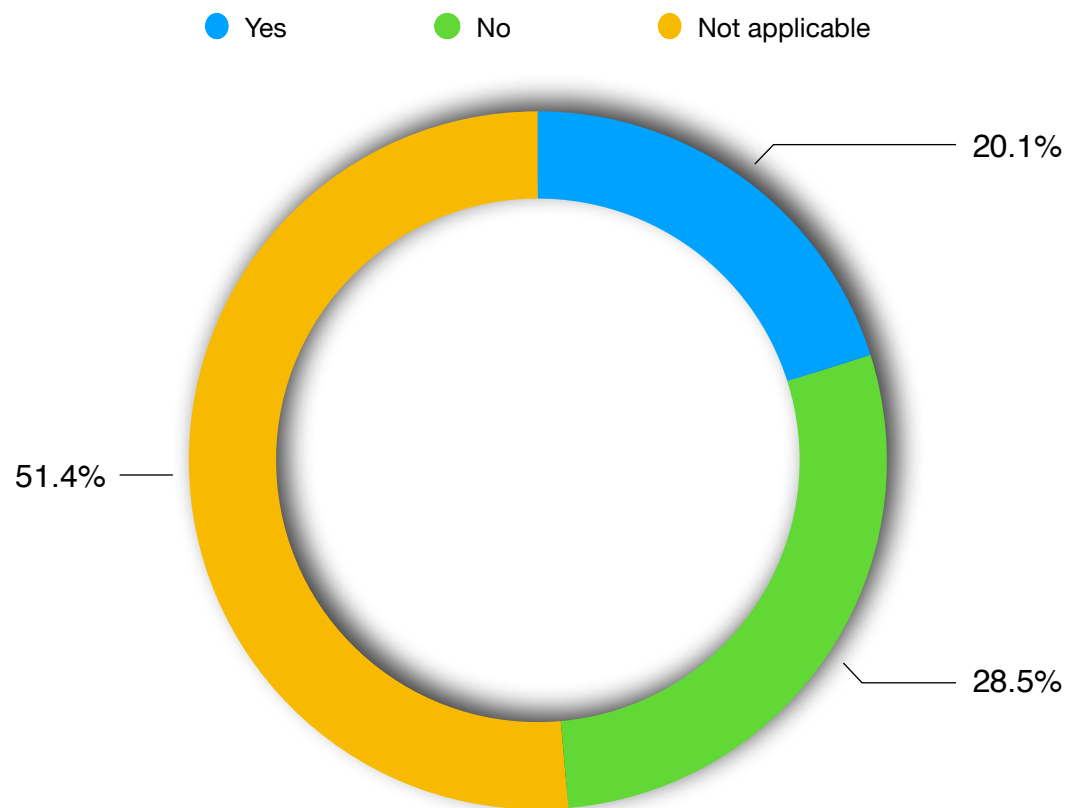
"I live with two other people who were leaving the house frequently."

Chart 14- Has lock down impacted on your ability to:



Though all of these would seem prevalent for most of the population during these uncertain times, the ability to exercise and ability to access the foodstuffs you need is particularly important for someone with sickle cell. Nutrition and dietary needs are an integral component in managing one's condition, this in conjunction with being able to exercise to maintain a fit and healthy lifestyle. Furthermore, it is a worry for those whose employment, sometimes at the hands of unscrupulous employers whose awareness of sickle cell and general disposition towards government guidance is placing our members at risk.

Chart 15 - If you have experienced a crisis, have you felt comfortable/safe enough to utilise A&E?



35.6% of those who have had a crisis said they have not felt comfortable/safe enough to utilise A&E. This really concerning development means there has been evidence to suggest that service users have been delaying hospital visits and appointments out of fear of contracting the virus. There are safety measures and safety precautions that hospitals are taking such as hot and cold zones. It is of paramount importance that people do not delay presentation and seek treatment when necessary. It is the role of government to make this clear to the sickle cell population as over a third of respondents have had to endure a crisis without the appropriate pain management required.

In free text responses respondents were offered the opportunity to elaborate:

"It's too high risk. I can't trust every other individual in A&E is obeying lockdown rules as strictly as I am."

"Getting flashbacks and A&E service is not great"

"I just feel people who are asymptomatic might be in A&E and going there may expose me to the virus."

"Worried of catching Covid-19."

"I've had to manage the pain at home with medication, to avoid having to go to the hospital especially during the covid-19 peak. Luckily it didn't get to a stage where I needed to seek medical attention."

"Stayed home too fearful to go to hospital."

"My hospital had a lot of COVID-19 deaths. I was hoping I did not get sick during the lockdown. If I did, I would have tried to manage it at home and still avoided hospital."

"Went to ed they had no facilities for me there, I told them I was in shielding, but I was left in the waiting room all the other people."

"I know people that have gone to hospital, contracted covid-19 there, and died."

"How has your income been affected by the COVID-19 pandemic? Have you been able to access the welfare assistance you need? (PIP, ESA or furlough payment etc.)"

Chart 16 - Have you experienced any positive impacts from lockdown?

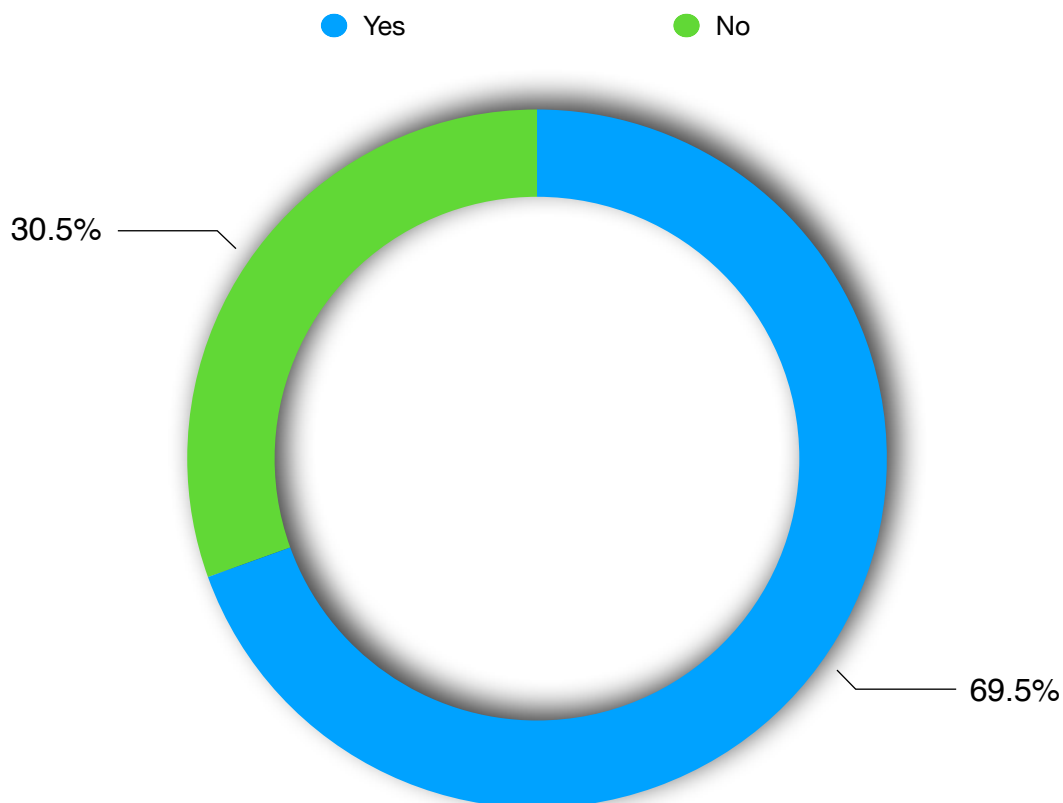


Chart 16 shows 69.5% of respondents felt there have been surprisingly some positive outcomes such as people being able to spend more time with family, spending less money and reducing their carbon footprint.

Q. How has your income been affected by the COVID-19 pandemic? Have you been able to access the welfare assistance you need? (PIP, ESA or furlough payment etc.)

There has been an overwhelming sense of anxiety over expected incomes and apprehension on whether support will be guaranteed in the medium to long term. In addition, the delays in being able to access welfare assistance has been problematic.

In free text responses respondents were offered the opportunity to elaborate:

"Yes, my income has been affected, I can't work and can't be furloughed due to umbrella company."

"Somewhat doing a few things from home so still getting my salary. My manager is quite understanding. I'm not too sure how much longer I would be able to continue not doing what I was hired to do with the same benefits. There's so much uncertainty. And as a non-citizen, I don't think I would be entitled to any government benefits."

"I've been told I'm not eligible since I'm a student but being home with my family, where my mother's income was drastically affected forced me to pay for things in the house. My employer was going to put us on the furlough scheme, but they ended up going into administration and making us redundant. I applied for PIP around mid-March and I'm waiting for a response from the DWP. I'm currently on Universal Credits which is not enough to live on."

"My employer had managed for me to be able to work from home at the moment but not sure how long this will last."

"My partner income has been affected. We are now accessing benefits."

"My contract terminated due to COVID19, and I was not able to access any support. Not a registered carer therefore no assistance available."

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