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## **Disproportionate Impact on People with Sickle Cell Disorders**

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We are writing as researchers who have been doing social science research with people with sickle cell disorders (SCD), their families and charities in the UK and internationally, and we are very concerned about how the COVID-19 pandemic is affecting them.

- There are 14,000 people with SCD in the United Kingdom (UK) and they predominantly belong to the Black, Asian and Minority Ethnic population, often living in families and communities disproportionately impacted by COVID-19 in areas of employment, housing, nutrition, leisure, education, health and social care, transport and energy as well as discrimination and institutional racism.
- People with SCD are among those who have been asked to shield because they have underlying health conditions but we have been concerned about public health messaging, shielding letters and the correct identification of who is high risk.
- COVID-19 is extremely dangerous to someone with SCD because hypoxia is a major cause of a sickling crisis which on top of COVID-19 symptoms can lead to co-morbidities of acute chest syndrome, stroke, organ failure and death.
- Many people with SCD rely on regular blood transfusions. Blood types for much of the BAME community was already in short supply and has now become even harder to access due to less people able to leave their homes to donate blood.
- The charities and social networks people with SCD rely on for information, education and aid have been affected and are in very precarious financial straits. This is partly because this condition has been largely marginalised due to it not being a major concern for the majority white British population. As these organisations are hugely reliant on support from BAME communities, they have been doubly hit by the impact of the pandemic as this population has been disproportionately affected economically and socially.
- The impact of the Corona Virus Act of 2020 also applies to people with SCD who may not self-identify as disabled but as having a chronic, genetic or inherited condition. In addition to negative experiences with PIP payments, universal credit and jobseekers allowance, many have been told they do not qualify as being officially disabled, partly because of the large number of errors in general and partly because SCD, and the multiple health complications it can lead to, is not a well understood condition.
- Women with SCD and who have children with SCD need more practical and mental health support than the general population.
- We are particularly concerned about those people with SCD who are self-isolating/shielding alone at home, asylum seekers, refugees and those who are destitute.

## Disproportionate Impact

It is estimated that sickle cell disorders (SCD) affect 14,000 people in the UK (Dormandy, 2018). Sickle cell disorders (SCD) is an umbrella term for a range of recessively inherited blood disorders that causes haemoglobin to 'disorder' and form sickle cell shapes. This can include people with homozygous phenotype for haemoglobin (HbSS) but also a combination with other haemoglobin variants such as HbSC, HbSD and one sickle haemoglobin combined with a gene for beta thalassaemia. In one person the condition can present as chronic illness, another as disability and in yet another it is serious and life-threatening illness needing immediate hospital treatment (Dyson, 2019). The signs and symptoms of the disorder can vary but are usually marked by anaemia (fatigue) and intractable pain. Some of the signs of SCD are similar to those of COVID-19 such as fatigue, pain, shortness of breath and fever. Acute chest syndrome is a common complication with SCD and can co-exist with respiratory symptoms of COVID-19, causing an amplification of both and much more rapid deterioration. When a person experiences a serious episode of pain, they term this 'going into crisis' and it is essential that they access treatment quickly, as damage can occur in vital organs like the lungs, kidney and heart. The condition is genetic but is triggered by extreme changes in temperatures, stress and lack of hydration.

In the UK, people who have SCD are primarily from Black, Asian and Minority Ethnic (BAME) communities who have been disproportionately impacted by COVID-19 and are also more likely to be affected by structural inequalities and racism (Dyson, 2019).

- We need to understand the needs of people with SCD who belong to BAME communities in areas like employment (Berghs & Dyson, 2019), housing (Cronin de Chavez, 2015), nutrition (Hyacinth et al., 2010), leisure (Dyson et al., 2007; Kato, 2019), education (Dyson et al., 2010; Dyson et al., 2011), legal redress (Berrey et al., 2017; Sonik et al., 2018), health and social care (Streetley et al., 2018; Chakravorty et al., 2019; Dyson, 2019). For example, we have heard about people with SCD not being able to access welfare after losing their jobs or lack of reasonable adjustments being put in places so they can work from home, inability to access food parcels or supermarket delivery slots, no legal redress to challenge COVID-19 linked discrimination, fears of losing housing or not being able to heat their housing due to lack of finances, lack of understanding of their socio-cultural and religious backgrounds and SCD by outreach workers and volunteers, lack of suitably warm and accessible housing, inability to access leisure activities, issues with universal credit and direct payments, delays in getting prescriptions and fears about going to see their GPs or into hospital for life-saving treatments like transfusions.
- *An inquiry is needed to understand how differing populations and 'vulnerable' groups within the BAME communities have been impacted, families affected and healthcare professionals, personal assistants, care workers, support workers, social workers and frontline workers who are BAME in particular.*

## Issues with shielding letter and incorrect advice

- Shielding letters aimed at people with SCD have been sent out to the wrong people, resulting in some people being told to shield when they didn't have to and those who need protection not being advised of this nor have the letter to gain support for this.
- The guidance for the letter states '*People with rare diseases and inborn errors of metabolism that significantly increase the risk of infections (such as Severe combined immunodeficiency (SCID), homozygous sickle cell).*' (PHE, 2020). This wording is highly problematic, firstly by

only stating homozygous SCD (HbSS) this excludes other types of SCD (HbSC, HbSD, sickle thal. etc.). Also, by using genetic terminology, there is a potential for health workers dealing with the letters to be even less clear about what SCD is and who should be sent the letter.

- People with sickle cell trait (SCT) received the letter in error. People with trait carry the gene but do not have SCD. This was widely reported on different social media platforms and caused some people and their families to take extreme measures of shielding when this wasn't necessary. For some it meant losing their jobs because their employer would not allow them to work after being classified as high risk. There are 250,000 people with SCT in the UK and it is not known how many of these received the shielding letter in error.
- A double complication with people with SCT receiving the shielding letter is that it is being reported in the media that people with SCT could actually be at risk to COVID-19 (See Murphy, 2020) but there has been a lack of research evidence. It is argued, this is because people with SCT typically have between 35-45% sickle haemoglobin which can sickle in conditions of hypoxia. Some people with SCT have a history of SCT related complications (Naik, 2018), such as sickle crisis, joint pain, splenic infarction leading to a splenectomy (Goodman et al., 2014) and a very rare cancer that only affects people with SCT called Renal Medullary Carcinoma (Goenaga-Vázquez et al., 2018). A serious complication of hypoxia (e.g. caused by altitude or exertion) can exist for people with SCT and we also know COVID-19 can cause significant hypoxia. There have thus been calls in the press to hospitalise people with SCT earlier (Murphy, 2020). However, current health services do not recognise SCT as being symptomatic as in most cases research evidence suggests it is not. The letters sent out in error have thus caused much confusion, with people shocked to learn they were such high risk and for health care professionals who did not realise SCT could be symptomatic. It has been reported that those who asked for advice from their GP or haematologist were given a range of conflicting reasons why they got the letter. One reason appears to be that there are significant errors in coding in their medical notes and that some people with SCT have been coded as having SCD: *"Other codes, such as sickle cell trait, may also have a code for disease on their records, which has been picked up by the national data extraction"* (Jameel, 2020; Razai et al., 2020). This also leads us to question how many people with SCD (of any type) have errors in the coding in their notes and did not get the shielding letter because of this and the access to all the support services that go with it.
- *We would like an investigation into how many people with SCD didn't receive the shielding letter, the reason why they didn't, and how many people with SCT received the shielding letter in error and the distress that was caused unnecessarily by this. We would also like a review of the degree of coding error for SCD and SCT in medical notes and what can be done to correct this. A bigger review of coding errors and who was and wasn't sent the letter in error also looks to be necessary for the whole population.*

### **Charities and social networks**

- Insufficient nutrition is a trigger for a sickle crisis and we have heard of issues of supermarkets not being accessible to disabled people and not enough planning going into feeding vulnerable populations. Whilst supermarkets have been working hard to prioritise those with high risk letters, it is well known that the supermarkets could never have the capacity to deliver food to everyone self-isolating. Charities and support networks have been trying to help as many as they can to access food but they too have limited capacity. In

addition, some people do not feel they need charity and may feel stigmatised by this kind of support. The government could have got more involved in solving the access to food problem by, for example, setting up databases of businesses (such as catering wholesalers) that have temporarily changed their services to delivering groceries to people homes. Governmental food distribution services could have also been set up to ensure that not just the very high risk get help accessing food, and there are those who may be asymptomatic COVID-19 carriers passing on the virus in local shops, supermarkets and as volunteers.

- Much of the government communication has been made from an ableist position whereas we know that not everyone has access to social media, televisions, may understand messages and may instead need to have a phone call, sign language or messaging made accessible to their carer/s. This includes access to information in an accessible language with accessible formats. It is typically sickle cell charities and patient support groups that will do this work of translation but are currently not able to because of funding constraints.
- *We have noted in the last 10 years of austerity and cuts that many of the community networks and services that served this group of people have disappeared. This makes the organisations, charities and patient support groups that do exist so precious and they urgently need support. We recommend reaching out to these services with financial support so they can ensure their own self-preservation and pay staff, as well as continue to do the outreach work that is critically needed.*
- *We recommend that public health and all other communications linked to COVID-19 are made more accessible to disabled people and translated into languages other than English. Disability rights and basics of inclusion should be a necessary part of pandemic preparedness and responsiveness. We ask for an investigation why these basic rights have been flouted.*

### **Shielding and vulnerability**

- We have serious concerns about the messaging that the UK government has engaged in around COVID-19 in terms of vulnerability and shielding. If COVID-19 particularly affects elderly people or those whose health conditions make them vulnerable, we would like to have more positive messaging about how regardless of ethnicity, disability, underlying health condition, gender, age and so on people will be kept safe and cared for to the highest standards in hospital settings. That people have a right to life and life-saving equipment regardless of who they are and that their human rights will be respected.
- The government has not explained social distancing measures for people who rely on daily or life-sustaining care. We want the government to ensure that front line health and social care workers as well people who come into contact with people with SCD have access to testing, contact tracing and PPE. We are particularly concerned with people who rely on care, are in care homes or living in sheltered accommodation.
- If people are shielding, they need assurances that they can access their GPs and consultants virtually if needed, that hospitals are safe enough to access and that services that they depend on like transfusions are still being prioritised. We have heard that some people are scared that there might be blood shortages and that this is not a priority because they hear so little about this life-saving support.

- *We would like an investigation into how ‘vulnerability’ was created through lack of pandemic preparedness and because austerity policies and cuts to health and social care services.*
- *We recommend an investigation into the concept of ‘herd-immunity’ and why it took so long for the government to act to prepare the NHS and how this lack of preparation has affected BAME communities in particular.*
- *We recommend the collection of data on who dies from COVID-19 in hospital, care and other settings. We recommend testing, contact tracing, PPE and infection control measures are put in place urgently in care homes. We recommend more support for people in care and other homes so they can keep safe. We recommend that WHO guidelines are followed about how long people remain infectious and that measures are put in place for people leaving hospitals, in care and other residential settings.*
- *We would like to hear positive messaging emphasizing that people are of value and that we are all vulnerable because we are someone’s child, someone’s brother or sister, someone’s wife, husband or partner, someone’s grandparent, someone’s neighbour – someone’s ‘person’. We recommend more messaging about how we can care for each other and offer support to reduce vulnerabilities especially for people facing very long periods of shielding.*

#### **Impact of the 2020 Coronavirus Act**

- People with SCD may not view themselves as disabled and identify as having a genetic or chronic condition and may not understand that they will be affected by the 2020 Coronavirus Act.
- We have concerns about disabled people who are highly vulnerable being treated by people, like personal assistants, without PPE. We have also heard about people being discharged from hospital after having had COVID-19 but not going into isolation with a lot of unclarity about how long people can be infectious and if they then have immunity.
- We have concerns about adolescents falling through the cracks in terms of transitions to adult social care.
- We are concerned about the fact that only one doctor’s opinion is now needed to detail someone under the Mental Health Act and this is now indefinite.
- *We urgently request that workers like personal assistants, mental health professionals, social workers and carers are thought about when it comes to PPE, testing and contact tracing.*
- *We recommend greater clarity about how long people can be infectious but asymptomatic, how long people can be infectious after they leave hospital having recovered from COVID-19 and what social distancing measures need to be in place and for how long.*
- *The duty of care as outlined in the 2014 Care Act has been suspended and we ask that an investigation of this is undertaken in local authorities that withhold care or disregard care and support plans. Some forms of care for those most in need, which includes some people with SCD, are life-sustaining and cannot be suspended.*

- *The Coronavirus Act is an emergency measure and should be revoked if it is abused or there are serious failings. It is not enough that there is a six-month renewal or revocation. We recommend an independent body is created to oversee the impact of the act that can make recommendations, act as Ombud and report any human rights abuses.*

### **Women, advocates and carers**

- We note an increase of abuse and violence in home and lack of resources that are both BAME and disability inclusive.
- We note that many women will not be able to work and need to care for children with underlying conditions as well as provide home schooling. We are concerned that this is viewed as normal and there is a no reimbursement for those levels of care nor services in place to support these women.
- We have heard that people have a need for culturally sensitive mental health support but this is currently lacking and the services they depend on are under pressure.
- We have concerns for carers of people with SCD who will need to isolate themselves, as much as those shielded, so they don't pass on COVID-19 to those they care for, especially as testing is not available to confirm if have COVID-19 or not.
- When people are admitted to hospital related to their condition they often need to be accompanied, this is of course the case if the patient is a child but also due to the level of pain people with SCD have. In pain, patients are often not even able to communicate with health professionals themselves. We are concerned that advocates and carers are not able to support people with SCD in hospital.
- *We recommend resources and services for BAME women that are culturally sensitive and accessible in various languages as well as disability inclusive.*
- *We urge more mental health support for people who have shield themselves for what is looking like longer than 12 weeks. We note the need for gender sensitive as well as culturally sensitive resources and mental health provision targeting BAME communities.*
- *We urge an investigation into neglect of SEND provision and unequal impact of home schooling on BAME women.*
- *Women with SCD can also be carers for children with SCD. We urge more support for mothers looking after children at home and from services should they fall ill. We urge more support for carers and advocates for patients being admitted to hospital and assurances that they will be heard and listened too, as well as patients treated and kept safe. We urge the need for them to have access to testing, so they can keep themselves and the people they care for safe.*

### **Excluded vulnerabilities**

- We have concerns about people who are asylum seekers or refugees not being in contact with organisations that understand their conditions nor comprehend where to get help and support. We note the lack of accessibility of messaging for disabled people and lack of

targeting to communities who do not speak English. If they go into hospital with COVID-19 or a severe crisis they need an advocate.

- We wish to raise significant concerns about those people with SCD who are destitute and are particularly vulnerable to exploitation on top of getting COVID-19 because they are unable to shelter in safe surroundings.
- We have concerns about those patients that do not have carers to be able to look after them once they have been discharged from hospital and may still have additional care needs.
- *We recommend that public health messaging is made more accessible and equitable to all members of society.*
- *We have concerns that some people with SCD who live alone or are shielding alone may slip through the cracks. We recommend that health and social care services pay increased attention to their physical and mental health provision.*
- *We wish more attention for people who are homeless to ensure that they can access safe shelter, testing and medical care should they need it. This includes homeless who are being put up by friends or families and a solution to provide them with the shielded environment they require.*
- *We recommend that social workers and charities are required to pay extra attention to those people who may look well on the outside but have an invisible disability and can become socially isolated and ill very quickly. We recommend that they also think about post-hospitalisation care of these people.*

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