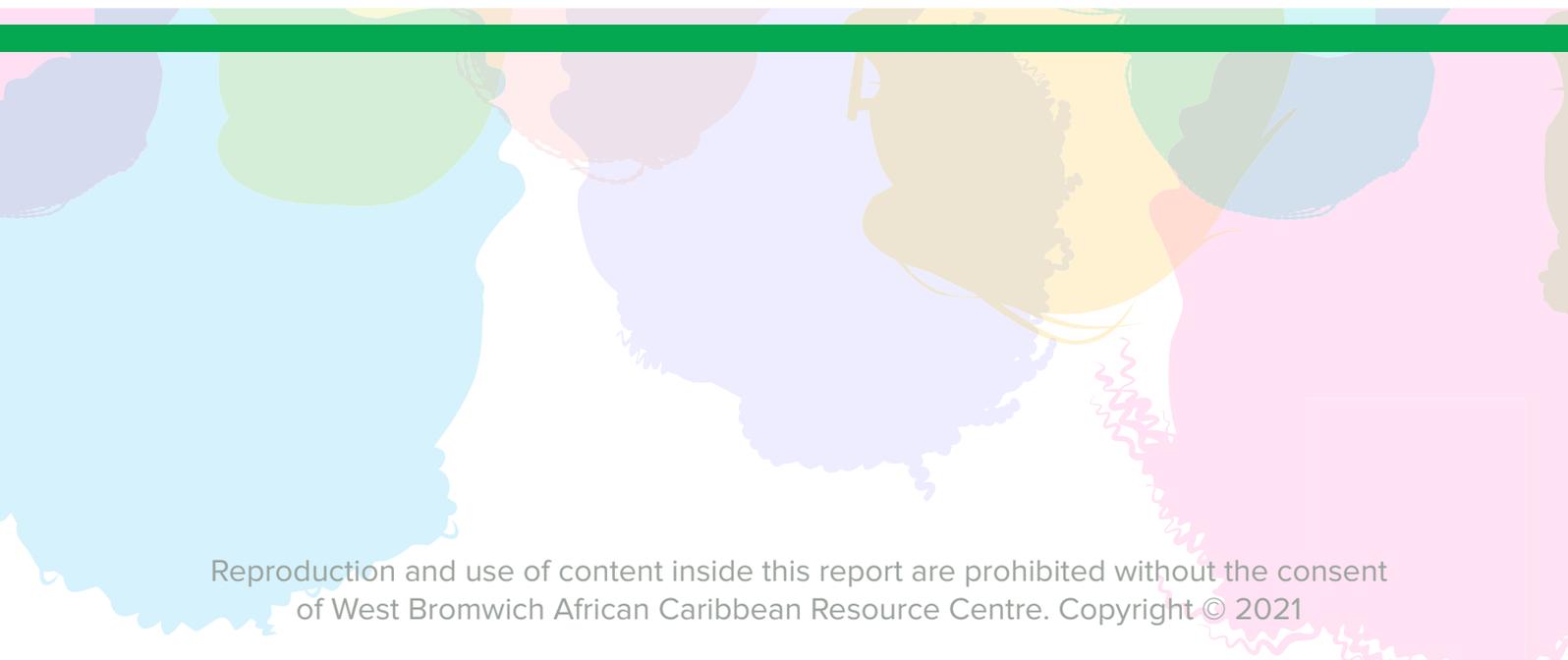


Black, Covid and in Lockdown: **In Our Own Words**

A community based research on the thoughts,
feelings and impact of COVID-19 and the lockdown
on Black african diaspora communities in
Sandwell, West Birmingham and the wider West Midlands



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In Loving memory of Andrea Ryan a dedicated carer

Gone But Not Forgotten



Report Authors



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Shane started working for Sandwell Health Authority in 1990 and after 5 years left his role as a Senior Health Promotion Officer to move into the charitable sector as the Chief Executive of West Bromwich African Caribbean Resource Centre (WBACRC). He holds a Master of Science In Health Promotion and has a keen interest in health and education. Shane has co-ordinated the research and his passion for black people telling their own stories is evident in the title of the research.



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Foreword



I am delighted to write the foreword for this report as it is a demonstration of Black African diaspora groups working together effectively to address an important area of public health. Now more than ever, we as a people need to come together.

That is why I helped to initiate community groups in Sandwell to come together to talk about the effects of the Coronavirus pandemic. I am delighted that I was part of the movement that did not allow it to become just another talking shop but resulted in positive action to have Black voices documented, listened to and heard.

The way Black African and Caribbean people are reported on has needed a revamp for a long time and I believe this report provides a refreshing approach by not allowing our experiences to be subsumed into the wider ethnic minority analysis. The outcome of which would not give succinct data which is important for all groups.

Whilst vaccine hesitancy is common knowledge the report goes further and identifies different factors in resistance and compliance that most reports ignore which enables more specific targeting for health planners.

The respondents have clearly endorsed the value of the support work provided by the third sector groups which is great to hear.

I am pleased to endorse this report and believe this will be the start of many self-generated research areas that Black African Diaspora groups will focus on in the future.

Finally, I would like to Thank all respondents for your time in answering the questions and for your real life stories that should never be forgotten.

Cllr Jackie Taylor
Cabinet Member for Sandwell MBC



Executive Summary

This community research was driven by the emerging data coming from the Office of National Statistics, which indicated that there were racial disparities in those being hospitalised with COVID-19 and racial disparities in the number of Black Asian and Minority Ethnic NHS workers dying from COVID-19. Whilst government reports focussed on the medical outcomes and statistics, we wanted to understand the impact and go beyond statistics and numbers by exploring how people from the Black African diaspora were experiencing COVID-19 and life in lockdown. Using a data collection survey, semi structured interviews and focus groups, we were able to identify a range of views. Some of our findings and recommendations include:

The research findings make the following points

- Black people, whilst cautious about the vaccines, have been wrongly portrayed as being anti-vaxxers. The follow up data showed that initial vaccine hesitancy did change over time, with some respondents later deciding to accept the vaccine. Cases where respondents originally declared that they were unlikely or very unlikely to take the vaccine was very specific to that moment in time. Many wanted to 'wait and see' based on the speed of the vaccine turn around and the inability to evidence the long-term effects of COVID-19 vaccines.
- Older people 65+ although vaccine hesitant were more likely to be willing to take a vaccine than younger people and there was a significant swing towards taking a vaccine when offered from those who were originally hesitant.
- We believe that the argument that social media has influenced people's decision making has been overplayed. Very few participants considered social media a reliable source of information and most placed a greater level of trust on mainstream news, in particular information coming from the NHS.
- MP and celebrity campaigns appear to have had little impact on individual decisions on whether to take a vaccine Targeted campaigns such as the video of the cross party group of Black MPs and members of the House of Lords and the NHS sponsored video of Sir Lenny Henry and other Black celebrities to encourage Black people to take a vaccine when offered were rarely cited by Black people as reasons why they decided to take a vaccine. Participants were most influenced by people they know taking the vaccine or wanting to prevent further restrictions if they were not vaccinated, for example, restrictions in travel and employment.
- Much more credence is given to Black Doctors and health professional giving information and answering queries.

- There remains a high degree of mistrust of government and the health services in the Black community. Historical deception is a prime reason for this, and the fear of these vaccines being used to continue to experiment on Black people.
- For younger people 18-35 a real barrier to wanting to take the vaccine is the fear of the unknown particularly in regard to future fertility and long term effects.
- Public health planners and policy makers will need to increase their knowledge and understanding of the impact of racial inequality and experimentation leading to mistrust of official announcements and campaigns. By doing this it will lead to better planning to address COVID-19 and other health concerns.
- Government, public bodies and businesses should use this opportunity to develop fundamental change as going back to normal is not something that many people from Black African diaspora communities want. There needs to be greater investment in Black led African diaspora community organisations to help increase resilience and better respond to such crises.



Introduction

From the outset, the intentions of the research was to look at Black people from the African diaspora and this was a deliberate intention to reject the popularism of the new term BAME an abbreviation for Black Asian Minority Ethnic.

In an effort to be clear who we are talking about the term Black African Diaspora Communities (BAFDC) is used as the default term which includes Black African, African Caribbean, West Indian, Black British and dual heritage and other groups who have Black African lineage.

When making the application for funding to the National Lottery Community Fund we wanted it to be clear that the research was about Black people from the African diaspora. For many years this charity has sought to assert its identity and have the experiences of Black African Diaspora Communities (BAFDC) recognised in their own right and not as part of a wider gathering of ethnic minority groups of people who may share some common experiences but not all.

In our own words is the central theme of the research as all too often the voices and experiences of Black African Diaspora Communities is lessened when amalgamated into the relatively newly created terms like Black Asian Minority Ethnic (BAME) due to smaller numbers and less comparable social economic and political power.

How to use this report

The report is a community based, research approach and from the outset we emphasise that it is not academic. Due to the number of respondents 119 our research will not be recognised as statistically significant, but our findings are real responses and most importantly give an understanding of what Black people of the African diaspora are saying and why they are saying it. For policies makers to be effective they need to not only know what Black African diaspora communities are saying but understand why they are saying it.

The report is interactive in that it has direct links to articles and social media posts, newspaper articles and announcements that have been available during the lockdown period that assist the reader to get a deeper understanding of the context and what was happening during the lockdown period. In addition, we have several appendices for reference at the end of the report.

We will use direct quotes to emphasise a theme or provide a link to social media posts or newspaper articles to illustrate a point.

The research is written in a step-by-step style placing an emphasis on processes and approaches used so it can be replicated in other areas of community-based research.

The report uses the broad themes outlined in the semi structured interview schedule (**see Appendix B**) and builds on the responses to develop emerging themes. It uses direct quotes from participants whilst taking every effort to maintain anonymity unless that anonymity has been waived.

Process

Whilst the area of research is of great importance, we also emphasise the process that took place before and during the research period as we hope it can become a model for other not for profit community organisations to conduct their own research in areas of interest as a tool to generate informed data and assist their own organisational planning and identify community needs.

A covid timeline is in the appendices with the aim of putting the report into a wider context.

What is different about community research is it does not necessarily start with a hypothesis as is the case with academic research. Instead, it starts with a microphone and listening ear, pens, paper and time for the participant to express themselves. This research is not only interested in the answers but the reasons behind the answers.

For Black African diaspora organisations, it allows an element of self-definition and is prepared to let Black voices be heard. This also gives the research a level of independence as the editorial control lies with those conducting the research. **“Those who hold the pen writes the story”**. It has long been felt that all too often research is done to us rather than bodies enabling and encouraging Black African Diaspora community groups to do their own research. **We are not only interested in what is said but also why it is said and what happens once it is said.**



Who we are

Lead Body

West Bromwich African Caribbean Resource Centre (WBACRC) is an independent community based local charity established to support the needs of the local African Caribbean community and local people. In operation since 1985, it became a registered charity in 2002. Its specialism is within the health and social care field with a particular emphasis of working with older people. In addition, it also works to support vulnerable people and its prime responsibility is to promote and preserve African Caribbean heritage. With a focus on health, social care, welfare, education and employment the charity has been involved in a range of areas that affect life chances. WBACRC has a history of research and community involvement since forming in 1985. Over the years WBACRC have established itself as a charity that seeks to positively impact the areas that affect the life chances and opportunities for people of Black African Diaspora origin and the local community, building up a range of research in areas including school exclusion of African Caribbean pupils in 1998.

www.wbacrc.org.uk

<https://www.wbacrc.org.uk/content.asp?id=106>

WBACRC have also supported Post Graduate level research into attitudes to organ donation.

<https://www.wbacrc.org.uk/media/attitudes-towards-organtissue-donations-within-ac-communities-catherine-hodge-oct-2017.pdf>

Delivery Partners

Sandwell African Caribbean Mental Health Foundation was established in 1994 and their vision is the best quality of life for people who are affected by mental ill health. It aims to be a leader in the delivery of holistic, recovery-focused, culturally responsive mental health services for, predominantly, but not exclusively, people of African Caribbean origin affected by severe and enduring mental ill health. They have a track record of innovation in the delivery of mental health support services.

www.sacmhf.co.uk

Organisation for Sickle Cell Anaemia Research (OSCAR) Sandwell was founded in 1988 and became a registered charity and company limited by guarantee in 1999. OSCAR Sandwell work together with local people with lived experience of Sickle Cell and Thalassaemia as well as voluntary and statutory services and stakeholders to improve the quality of life for people affected by Sickle Cell and Thalassaemia in the Sandwell area. OSCAR Sandwell provides counselling support, advice and guidance, and training telephone support. Due to COVID-19, home visits and hospital befriending has ceased for the time being.

<https://www.oscarsandwell.org.uk/>

Bethel United Apostolic Church UK provides support to its congregation, spiritual care and practical care and support. It is a large network of 42 Black majority churches across the North, Midlands, Southeast, Southwest and Wales. They deliver hospital ministries, ward visits and partner with the Well Food Bank and Centre Point to support the most vulnerable facing homelessness and food poverty.

<https://betheluniteduk.org.uk/>

Cape Community Day Care Centre is a dedicated day centre which part of Cape Church providing emotional support and activities for older people within the locality twice a week, catering for up to 50 elderly people, the most frail and vulnerable with mental illnesses and isolated in their homes.

www.capecaringcentre.co.uk



The Research Topic

Factors that prompted the research were driven by the emerging research coming from the Office of National Statistics which indicated that there were racial disparities in those being hospitalised with COVID-19 and that there were racial disparities in the number of Black Asian and Minority Ethnic NHS workers dying from COVID-19.

“Our statistical modelling shows that a large proportion of the difference in the risk of COVID-19 mortality between ethnic groups can be explained by demographic, geographical and socioeconomic factors, such as where you live or the occupation you’re in. It also found that although specific pre-existing conditions place people at greater risk of COVID-19 mortality generally, it does not explain the remaining ethnic background differences in mortality.”

*Ben Humberstone, Deputy Director, Health and Life Events Division,
Office for National Statistics*

What it did not explain was why Black doctors and nurses who are not in the lowest economic brackets were also experiencing higher rates of death and hospitalisation than their white counterparts.

Coronavirus: 72% of healthcare worker deaths come from BAME backgrounds

<https://www.youtube.com/watch?v=rROXzufhMBQ>

It was not long before the question of Black people and the impact of the coronavirus started to emerge. Why were Black people being admitted to hospital in such high numbers? Why were so many Black hospital and care staff dying? This was exacerbated as reports started to indicate within the NHS that Black people were more likely to catch the virus and were more likely to be hospitalised as a result and ultimately were more likely to die from COVID-19.

The implications of early association of Black African diaspora communities with COVID-19 gave rise to a number of questions and assumptions. Were the high deaths rates a result of Black people having weaker immune systems? Were the high infection rates the result of overcrowded households? Were Black people not following basic hygiene practices. Were Black people getting poorer care in hospital and was this part of a plot to kill off Black people?

Why was this? Was there something about the virus that attacked Black people? Whilst reports focussed on the medical outcomes, we wanted to understand the impact which goes beyond statistics. How were Black people experiencing life in lockdown and COVID-19 and what has been the impact?.

Our organisational interest was further increased when Sandwell Metropolitan Borough Council and Sandwell and West Birmingham Clinical Commissioning groups started to make efforts to understand what was going on and both decided to base their respective

investigations within a BAME framework. As an African Caribbean focussed organisation, we found this problematic as we often feel some of the particular needs of African diaspora communities are not best represented within this wider BAME framework. This was heightened by the increase in news items related to coronavirus, not only on mainstream media but also the circulation of videos on social media. For example, in early April 2020 a WhatsApp video proclaiming that Black people do not get coronavirus raised concerns, especially as within weeks of this video emerging figures started to emerge in the UK that Black NHS staff were dying from coronavirus at three to four times the level of their white NHS colleagues. No risk assessments and comments about being too caring in their role, were all reasons offered for the discrepancy in the death rates of Black NHS staff.

As deaths started to be felt in the community individual cases started to be played out in the public. Added to these concerns was the feeling that the role of Black NHS staff and that of non-white staff was not being recognised. The theme was addressed by comic and social commentator Gina Yashere using the twitter trending hashtag #stopthewhitewash. Here, Gina Yashere denounced the racist behaviour of the press in depicting only white NHS staff when promoting the clap for heroes' campaign to praise and recognise the NHS. NHS figures indicate 20% of staff are from non-white backgrounds but their presence was not recognised by the press leads.

<https://twitter.com/i/status/1244215754146414592>

In the West Midlands, two video cases were circulated raising concerns on how hospitals were treating African diaspora elders. One included an elderly father being removed from a hospital after it emerged that he was put on a COVID-19 ward when he did not have COVID-19 leading to the family discharging him. Another case emerged where an elderly father had COVID-19 put on his death certificate when there was no confirmation of a positive COVID-19 test registered on the deceased prompting a relative to start a national campaign.

Sandwell MBC contacted the West Bromwich African Caribbean Resource Centre charity asking for comments on how African Caribbean communities were experiencing COVID-19, this was sparked by the emerging data on elevated illness and death rates. Whilst being recognised as a trusted community organisation and having over 35 years' experience of working with African Caribbean communities, we were not able to offer an informed fact-based response to the question. The truth of the matter was there had not been any work done on the impact of the lockdown on the African Caribbean communities, so our responses were speculation and calculated guesses based on our experience of working with the African Caribbean community.

As the early statistics started to indicate racial disparities in hospital admissions and ultimately higher death rates, the urgency of getting to know how COVID-19 was impacting Black African diaspora communities became more important. It was at this point that a decision was made to apply to the National Lottery Community Fund to conduct some research on this topic. Having participated in a new group to look at matters arising from the George Floyd killing and the impact of the Black Lives Matter demonstrations, the idea was floated, and potential partners were pre-warned of the possibility of being part of the research if the application was successful.

Community Research not Academic

We deliberately chose not to follow an academic pathway to give a bigger voice to those participating and sharing their stories to effectively open the door so the people we seek to benefit can be heard.

Meaningful data on Black African Diaspora communities has been traditionally difficult to get within the public bodies, largely due to difficulties in categorising or in other cases a lack of committed action. The system is slow to come to grips with multiple identities so there is an either-or approach. In reality, we have multiple identities, we can be Black British, African Caribbean and from the African diaspora. As an example, there is no space to record the ethnicity or “race” of the deceased on death certificates nor is there a nationally agreed format for recording patient’s ethnicity in GP records.



Process and Methodology

When looking at the research we wanted to start with some underlying principles to ensure that it was meaningful. For the community it was vital that we value their experiences, engender trust, show some recognition and make it useful not just to policy makers but to Black African Diaspora communities.

Values

Above all else we wanted to ensure that participants and delivery partners felt valued. The proposal built in recognition payments for those individual participants and more substantial payments for the delivery partner groups who would be carrying out some of the focus groups and individual interviews. Participants were also given the option of receiving a recording of their Zoom interview as well as the opportunity to withdraw their consent.

Respect

As with all research, respecting privacy is of the utmost importance so we allocated numbers to individuals to avoid chances of identification. It was important to build in flexibility, so interviews were held at a time to suit the participants and included evenings and weekends. Our position was not to be judgemental in the responses we received to the questions asked, and zoom interviews were conducted with cameras switched off to avoid nonverbal communications potentially affecting responses. On a practical level this required understanding the medical ethic of 'do no harm' and ensuring that participants were giving informed consent.

Building the team and partner engagement

Like most projects the success is determined by getting the right team in place performing roles that they can be most effective in. Convincing partners of the benefits of the research project to them as individual groups were not difficult as we were all concerned about the impact of COVID-19 and the lockdown on Black African Diaspora communities. It was essential that these groups had cultural and historic understanding of the target population but also had an interest and most importantly sufficient internal capacity to embark on the research.

Using local and existing knowledge the delivery partners were identified based on their organisational capacity, reach into the community and understanding of the issues. We were able to gather a cross section of organisations which were faith based or working with specific health conditions and covered a range of age groups.

The first task was to pick a good team that could deliver the project. Using prior experience of collaborative working, the five organisations became part of the research team. We wanted partners to be involved on a manageable level without feeling burdened as we recognised that they had their own regular day to day work to do.

Training for Partners

It was identified that there needed to be some training established as there were different levels of computer literacy and competence in regard to Zoom meetings but thankfully the chosen partner representatives had some prior experience of conducting research. A training session was set up using Zoom to explain in more detail the aims of the project and to provide some training in the use of Zoom technology to record audio and written transcriptions. At the training session a mind map was created on the theme of the research which was then shared and used as a basis upon which to construct the semi-structured questionnaire. The training covered demonstrations on how to use Zoom, including how to set up transcripts and audio recordings, as well as how use the online questionnaire format SurveyMonkey to generate data. Individual partner agreements were discussed, and draft agreements were shared after the training. Partners were also invited to comment and suggest amendments to the draft semi-structured questionnaire. Individual group representatives needed a follow up Zoom meeting to answer queries from the training and boost confidence where required.

All partner agreements identified the numbers of interviews or focus groups required and a payment plan. To support organisational cashflow, partner payments were made at the beginning of the research period, in the middle and at the end in three equal measures. A participant recognition voucher was built into the research equal to the value of £20 as a token of recognition for their time.

When looking at the most effective methods to carry out the research we had to consider the target respondents and use our knowledge and experience of working with Black people from the African Diaspora communities. Although our charity serves a cross section of the community, the partners enabled a greater reach into the target populations. Using our networks, we identified four groups to approach that would give us a cross section by age, residence and other factors that could show an acceptable level of community representation. We also had to review our own use of digital platforms and increase our understanding of them.

The original proposal estimated an involvement of up to 80 people made up of individual interviews and focus groups.

Choosing the research tools

Originally, we had proposed to use the SPSS software popular amongst social science research, but it soon became apparent that this was not the most appropriate platform and the decision was taken to use the NVivo software to help analyse the semi structured questionnaires that we were to use. NVivo is a qualitative data analysis software package which allowed for coding to be given to individual transcripts and focus groups, which in turn allowed us to generate themes.

There were practical considerations and restrictions brought on by the lockdown and the social distancing requirements, in particular the limiting of face-to-face interviews. As a result, it was decided to have socially distanced focus groups where it was not possible to do it over a digital format.

We wanted to ensure that we had a cross section of the Black African Diaspora community. Given the lack of digital connection of some older people we had to enable alternative data gathering methods, such as telephone interviewing.

Where required assistance was given by physically setting up phones and other devices to enable the zoom interviews to take place.

The data collection survey was used to gather specific individual data and was constructed to allow comparisons to be made for age, gender, job role, marital status and residency. In addition, the questions included categories to cover, health status, living arrangements, health arrangements and the first part of the post code to be able to see which part of the region participant respondents resided. Using the free SurveyMonkey research platform 10 questions were created to give an overview of the people who were being interviewed. The questionnaire was developed following a mind mapping exercise to think of all the issues that coronavirus could impact on as shown on the next page. After sharing the mind map with the partners, the semi-structured questionnaire was created and trialled with a staff member before being finalised.

As the research progressed other areas started to emerge and so another element was added to identify if there was any change in attitude towards the vaccines and if so, what was the reason for those changes and what influenced those changes.

Data Collection and Questionnaire Development

The data survey questionnaires were in both a digital format and a hard copy format. The introductory information was sent to participants via email and contained a link to the SurveyMonkey data questionnaire and a Word version was also emailed. In the event that it was a telephone interview, the questionnaire could be completed immediately before the semi-structured interview.

We used some of the best practice principles that are common to academic research. From the start participation was voluntary and anonymous and all participants were explicitly informed of the right to withdraw as emphasised in the participation information sheet and were reminded of this prior to interview. This ensured that there was informed consent and the right to withdraw. Prior to interview where practicable, individual participants were sent an email with a participant information sheet, a consent form and a link to the data survey as well as an emailed data survey form in a Word format.

Use of modern technology was key to be able to include a significant number of participants as well as have recorded interviews, online training, Zoom, interview schedules and information and consent forms.

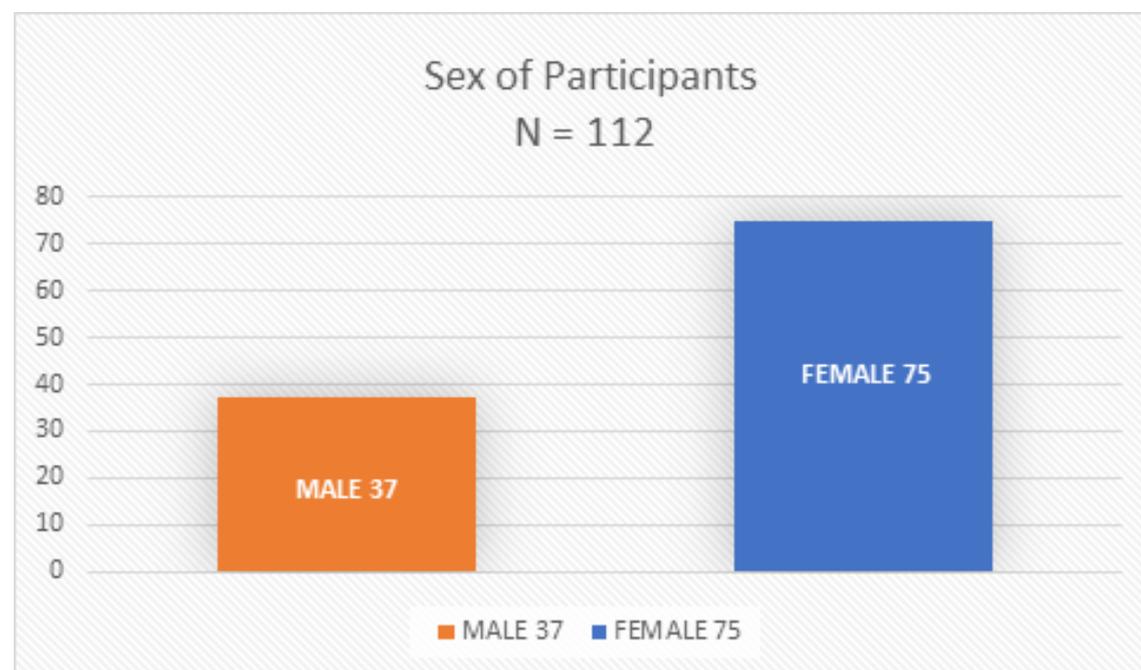
Due to the nature of focus groups, it was more difficult to gather the individual data from participants. Some data sheets were incomplete whilst some participants wanted to take part but declined when asked to complete the data survey. The participant figures are reflective of the number of one-to-one interviews and participants in the focus groups. As a result, there are some questions that have fewer responses than the actual number of participants. The graphs that are presented represent percentages in most cases and the number of respondents for that question.

Data Survey Analysis Overview

All interviews were held between December 2020 and February 2021. In total there were 119 participants who completed one-to-one interviews or participated in one of the focus groups that were held. Of those, 110 completed all or some part of the data collection survey and the differences between the 119 participants and the 110 completed data surveys were largely the result of different focus group preferences. Some participants were unwilling to give personal data for reasons of trust. The length of individual interviews ranged between 17 minutes and two hours and 20 minutes. On average most interviews last approximately one hour.

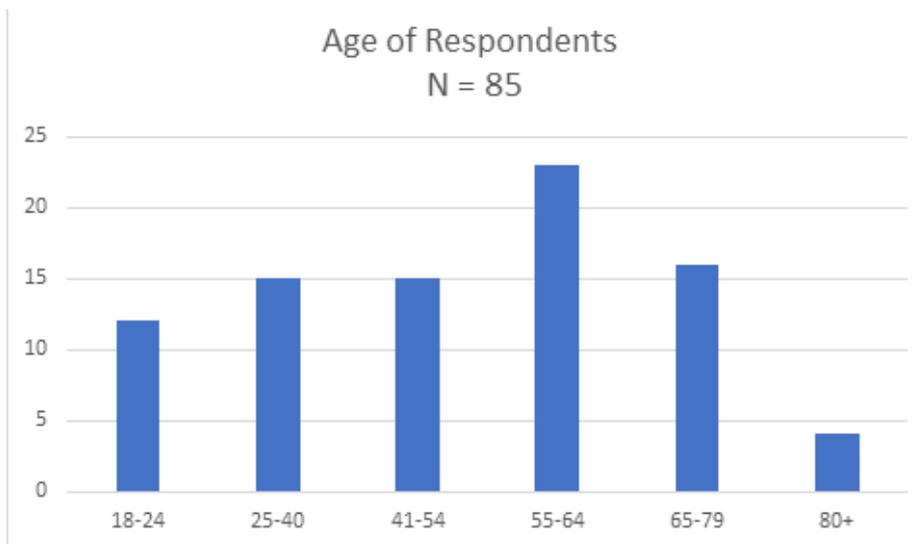
Sex of Participants

There were more female participants, with females making up 67% of the total respondents. This was largely due to one of the focus groups being almost exclusively female and the over-representation of women within the 66 to 79 and 80+ age range.



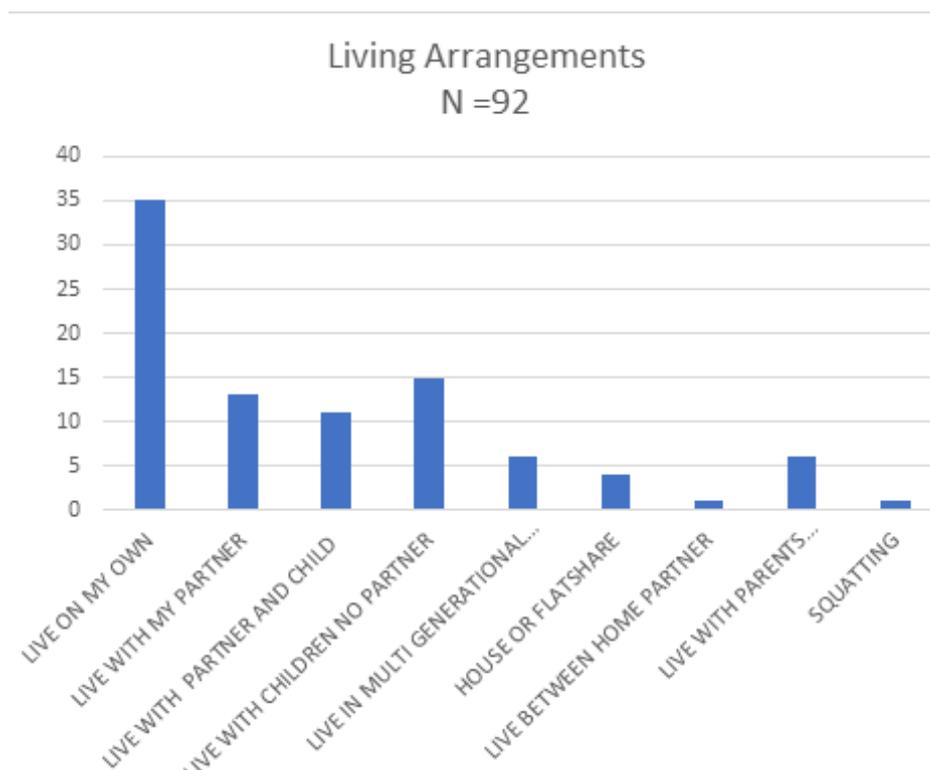
Age of Participants

The age distribution across the sample was quite representative of the population with the under 40's making up 25% of the total, and the 41 to 65 age range making up 35% of the total. Due to the small number of respondents within the 80+ age range, some of the responses were merged to create a 65+ category. This 65+ age range accounted for 18% of the total.



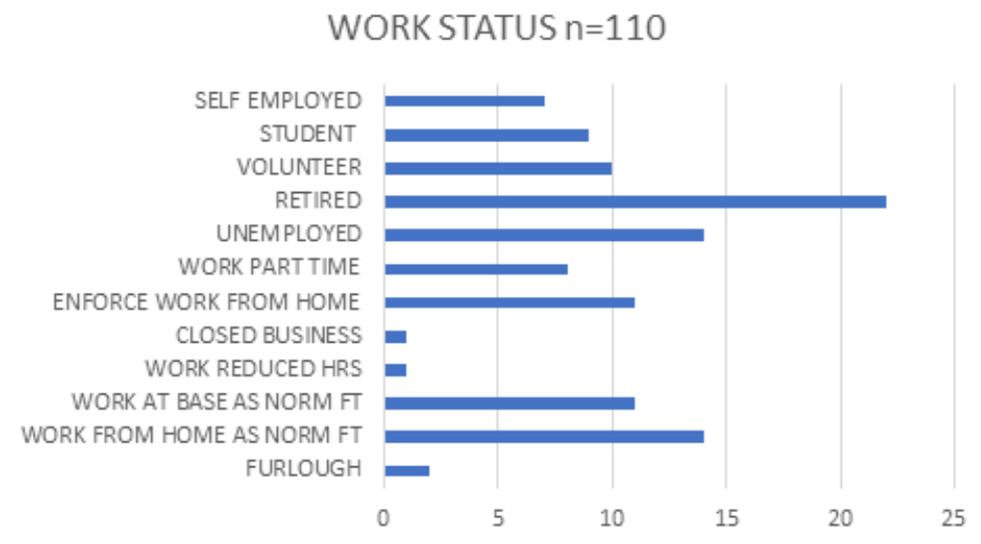
Living Arrangements

Over 36% of the respondents lived on their own which was the highest category recorded. 14% of respondents lived only with their partner, 21% lived with their partner and child(ren). 16% lived only with their child(ren), 6% stated that they were living in a multigenerational household, which could be an indicator of overcrowding. Explanations of higher covid contraction within BAME communities often cites overcrowding and high numbers of multigeneration households but these issues do not seem to be as relevant when looking at Black African diaspora communities.



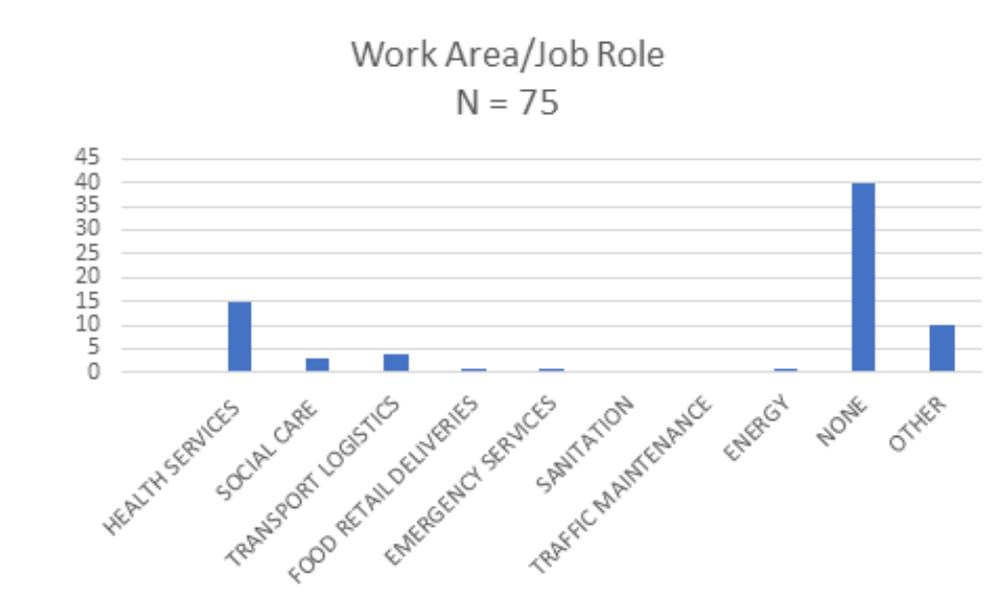
Employment Status

Just under 25% of respondents were either working from home as normal or working from base as normal so had no real change. Only 2% were benefiting from being on the government furlough scheme and less than 1% were working reduced hours. Higher numbers were working from home as normal or from base as normal with only 10% having to work from home by the employer. 20% of the respondents were retired. Not including those who were retired, those who were unemployed at the time of the interview made up 16% of those eligible for work. This is substantially above the general population national average. A high number of those who were unemployed had the genetic condition of Sickle Cell Anaemia.



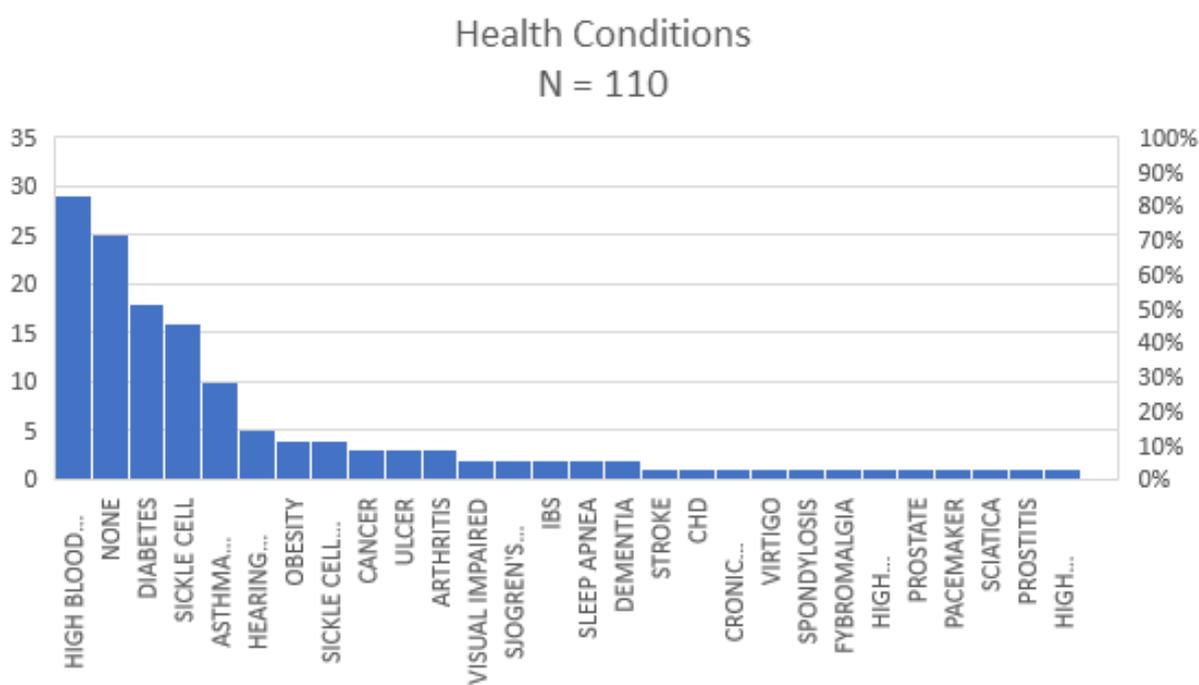
Work Area/Job Role

A total of 75 participants responded to the question on job role. The total number was lower than most survey questions because 22 out of the original 110 who completed some or part of the data survey were retired. 53% of respondents indicated that they did not work within the essential services. Of those who worked in essential services, health services accounted for 42% of respondents job role.

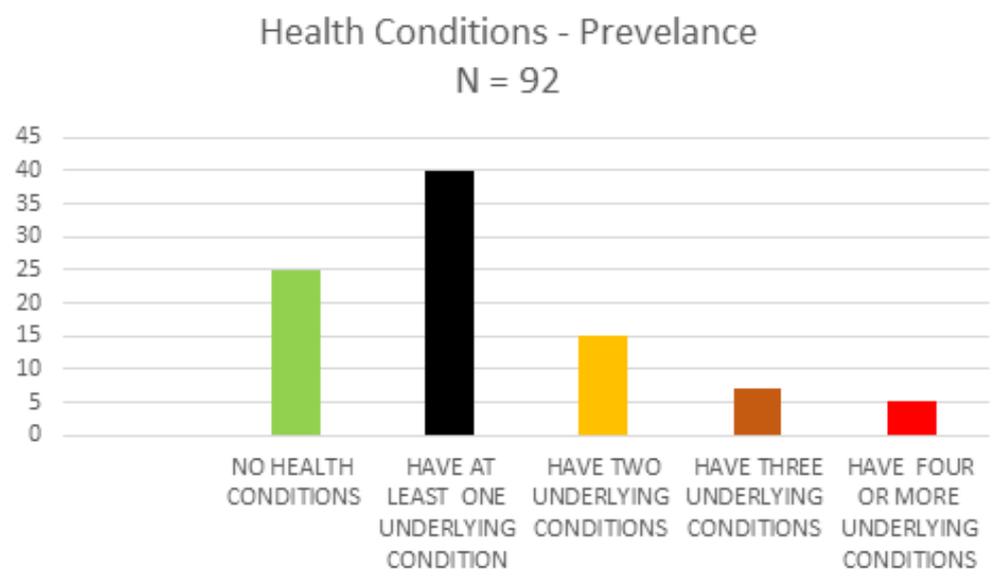


Health Conditions

There were 110 responses to the question on health conditions and a total of 28 different conditions were experienced by respondents. High blood pressure was the most common condition and accounted for 26% of those mentioned, followed by Diabetes at 16%, Sickle Cell Anaemia at 14% and Asthma/respiratory conditions at 9%. The importance of identifying the health conditions that respondents experienced was due to the strong relationship between COVID-19 survival rates and the health status of the individual. 41 respondents informed us that they had no health conditions, and these were largely located within the 18 to 24 and 25 to 40 age group. Diabetes was found predominantly within the 41+ age range. High blood pressure was identified mostly in the 54 to 64 and the 65+ age ranges. People with diabetes, asthma, high blood pressure/hypertension and obesity were more likely to be asked to shield by NHS/ local government correspondence.

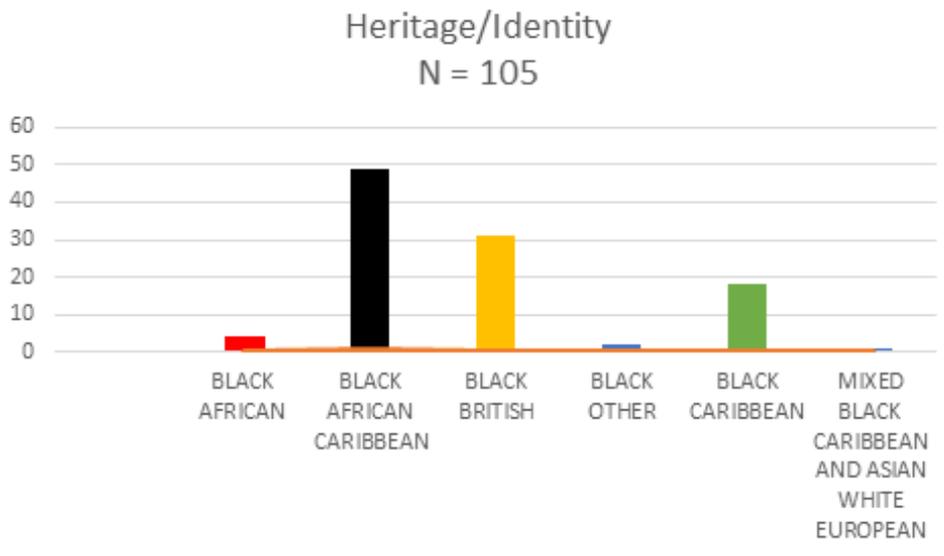


Some respondents declared that they were experiencing more than one condition. 45% of respondents reported at least one health condition, 16% reported two underlying conditions and 13% reported three or more underlying conditions.



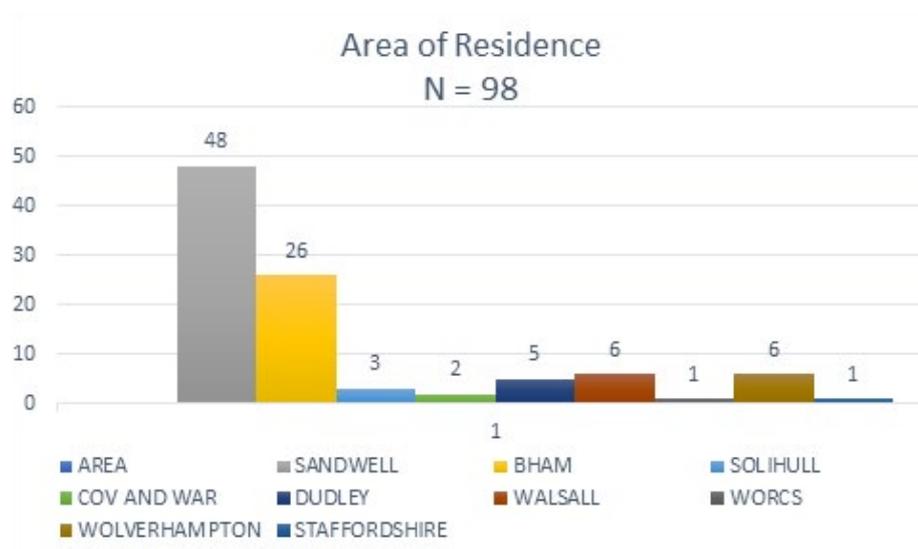
Heritage / Identity

Participants were asked about their heritage and identity. Black African Caribbean was the most popular term followed by Black British and then Black Caribbean. Black British was the most popular terms used by the 18 to 24 age group, and Black Caribbean was the most popular term amongst the 65 to 79 age group. Black African Caribbean was common across all the age groups and a smaller number gave themselves more than one identity. An individual can see themselves as Black British as well as seeing themselves as African or African Caribbean. Many people of dual heritage also identified themselves as African or African Caribbean. A few recorded as many as three heritage options.



Area of residence

There was representation across boroughs that make up the West Midlands region, with Sandwell having the highest number of respondents followed by Birmingham. Of the 98 respondents to this question 75% resided within the boroughs of Sandwell (49%) and Birmingham (26%). Of the remaining 25% Walsall and Wolverhampton had the highest number of participants with 6 each followed by Dudley with 5. Then Solihull, Coventry, Warwickshire, Staffordshire and Worcester had the lowest number of participants varying from 3 and under.



Vaccination is a major part of a wider public health strategy to limit the impact of the COVID-19 virus and sits within a mixed bag of measures that include public education, public engagement, behaviour restrictions using guidance and behaviour restrictions using legal enforcement. The immediate objectives are to limit death and limit the spread of the COVID-19 virus and its variants. Early indicators showed that death was concentrated in the over 80's population living in care homes, those with learning disabilities and those in positions that require close contact with the public. As a result, the government prioritised vaccination for health and social care workers, transport workers, those aged 50 and over, and the clinically extremely vulnerable as these groups accounted for 99% of deaths from COVID-19.

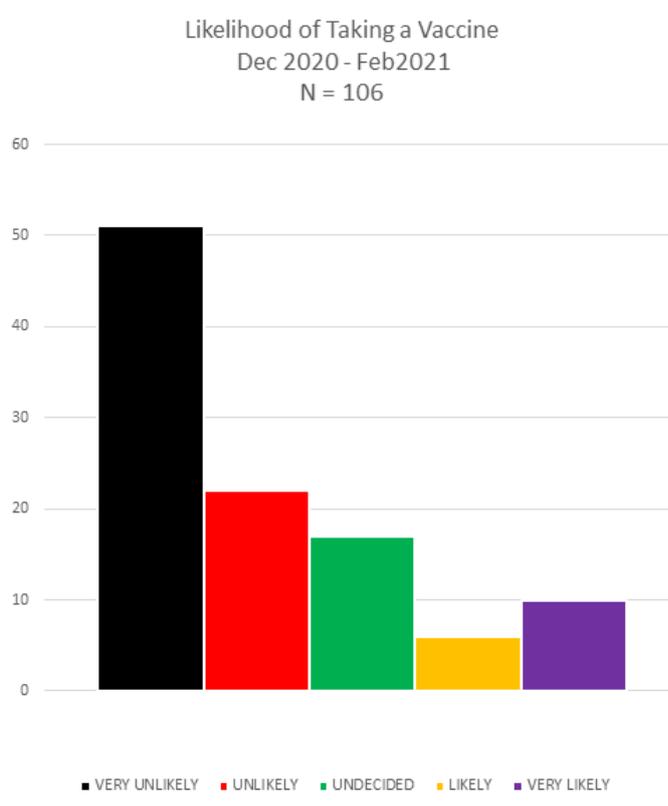
Vaccine hesitancy regarding COVID-19 was initially identified in the General Household Survey, sometimes referred to as the UK Household Longitudinal Study reference group who asked the question:

“Imagine that a vaccine against COVID-19 was available for anyone who wanted it. How likely or unlikely would you be to take the vaccine?”.

The possible responses to the above question were ‘Very likely, Likely, Unlikely, or Very unlikely’. They reported in June 2020 that in the Black Caribbean category 72% were either unlikely or very unlikely to take a vaccine once one was developed, with only 28% likely or very likely to take a vaccine once developed. This fuelled the concern around vaccine hesitancy. It is important to note that the survey took place at a time when no COVID-19 vaccine had been developed or approved. In this report, the term vaccine hesitancy is used to conceptualise those respondents who were either undecided, unlikely or very unlikely to take the COVID-19 vaccine.

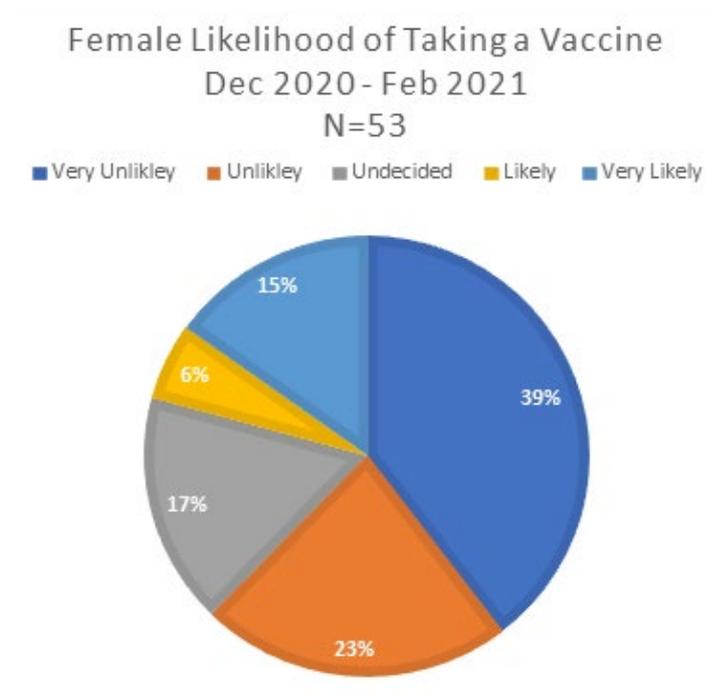
Vaccine positive refers to those who are likely or very likely to take a vaccine when offered. It also includes those who on follow up have confirmed that they have taken a vaccine. We wanted to explore issues around vaccines in more detail so our questions on the issues included views about whether taking a vaccine should be compulsory for all or just some and the reasons for their response. The numbers are not statistically significant, but they do point towards trends that could be explored at a later stage with larger samples.

When looking at relationship between Black African diaspora communities and public health bodies it is important to understand the context in which health bodies interact. Overcoming barriers is a major challenge and can be explained using the cycle below. The impact of racism is not only emotional but directly affects behaviour with mistrust being a major influencer on how the messages are received. Public health Interventions need to be able to address the mistrust of the public health messages and understand that this mistrust comes from lived experiences as well as less reliable sources. The messages will take time to get through and their desired outcome in this case vaccination will not be instantly acted upon.

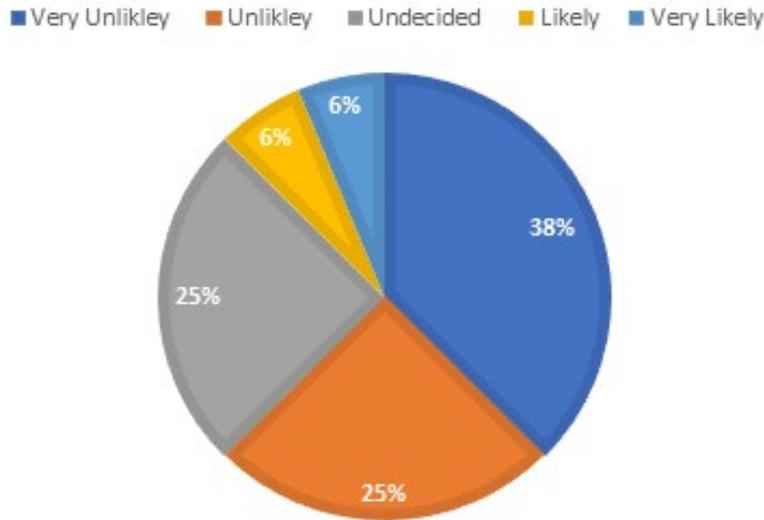


Sex of Participants

There was no major difference between the number of females and males who were unlikely or very unlikely to take a vaccine, 62% and 63% respectively. There was, however, a difference between those who were undecided, at a rate of 17% for females compared to 25% of males. There was also a difference for those who said that they were very likely to take a vaccine, at a rate of 15% for females compared to only 6% for males, indicating that females were more definite about whether they would take a vaccine or not.

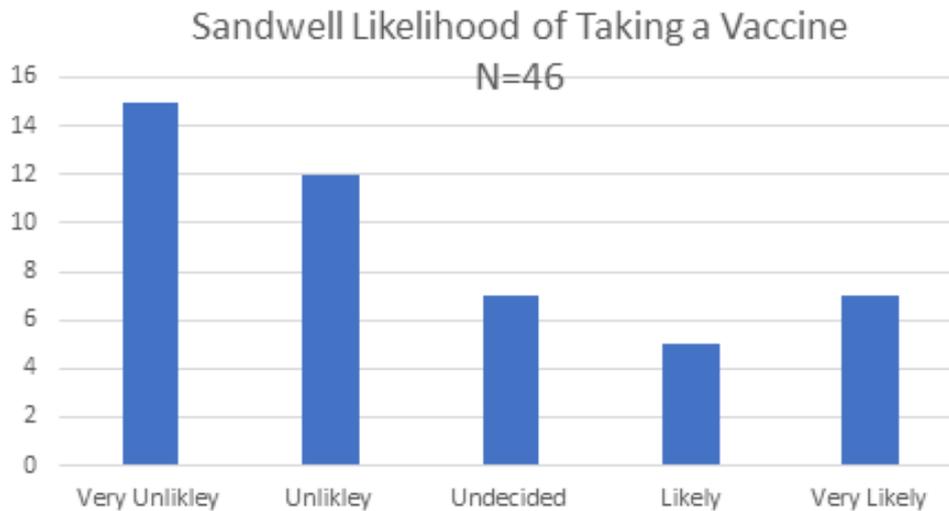


Male Likelihood of Taking a Vaccine Dec 2020 - Feb2021 N=32



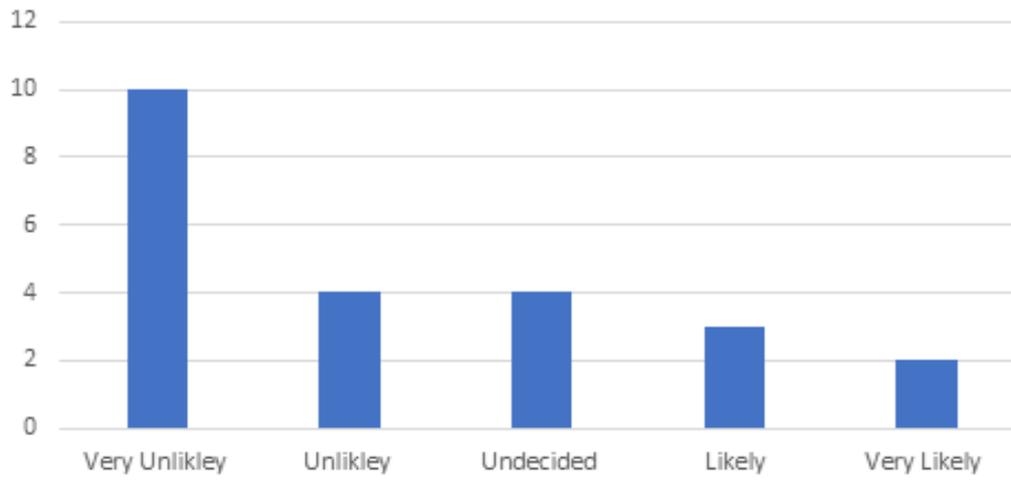
Area of residence

The number of responses for Sandwell residents was exactly double that for Birmingham respondents so when using the same proportions, we compared the two areas. Sandwell residents were 74 % vaccine hesitant compared to Birmingham residents who were 78% vaccine hesitant. Birmingham residents recorded a higher level of being very unlikely to take a vaccines and also for those giving 'undecided' responses, but Sandwell residents had a higher level of respondents who were 'very likely' to take a vaccine.



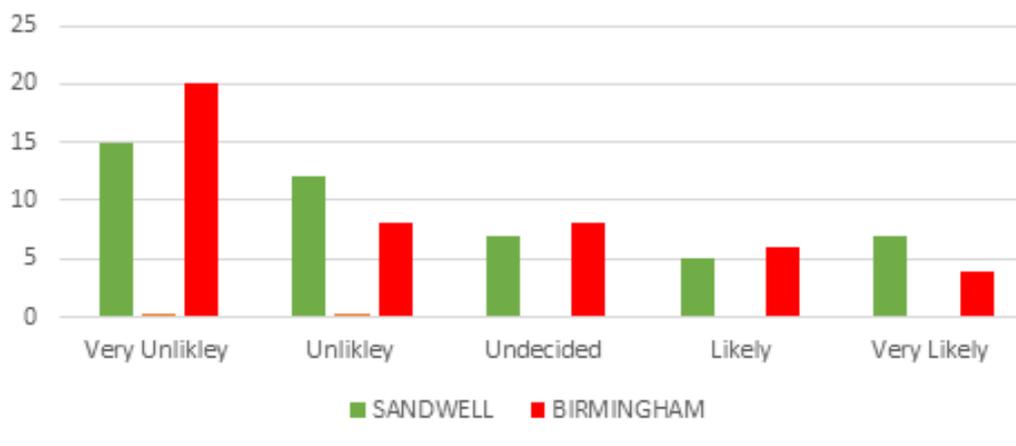
Birmingham Likelihood of Taking a Vaccine

N = 23



Comparison of Sandwell and Birmingham on the Likelihood of Taking a Vaccine

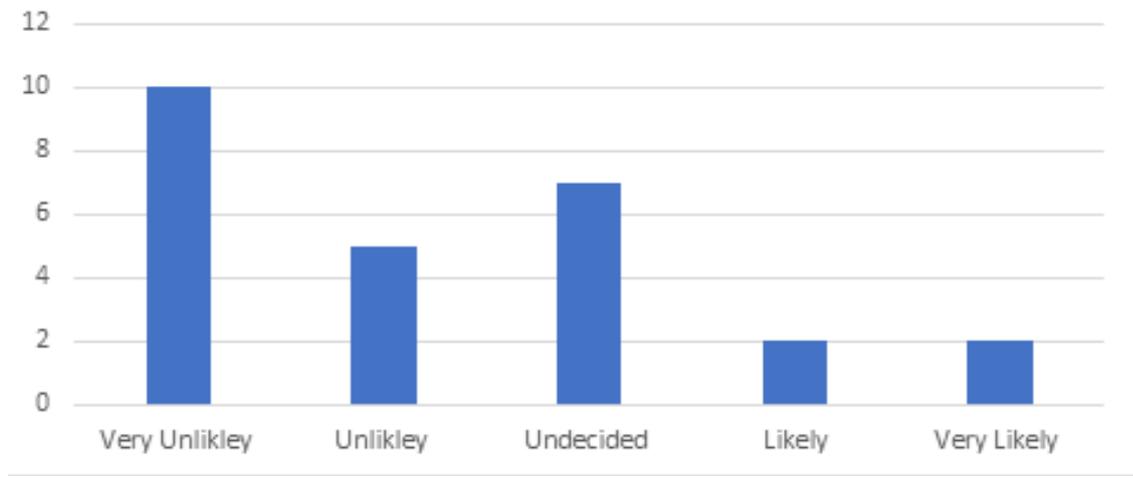
N=75



Living Arrangements

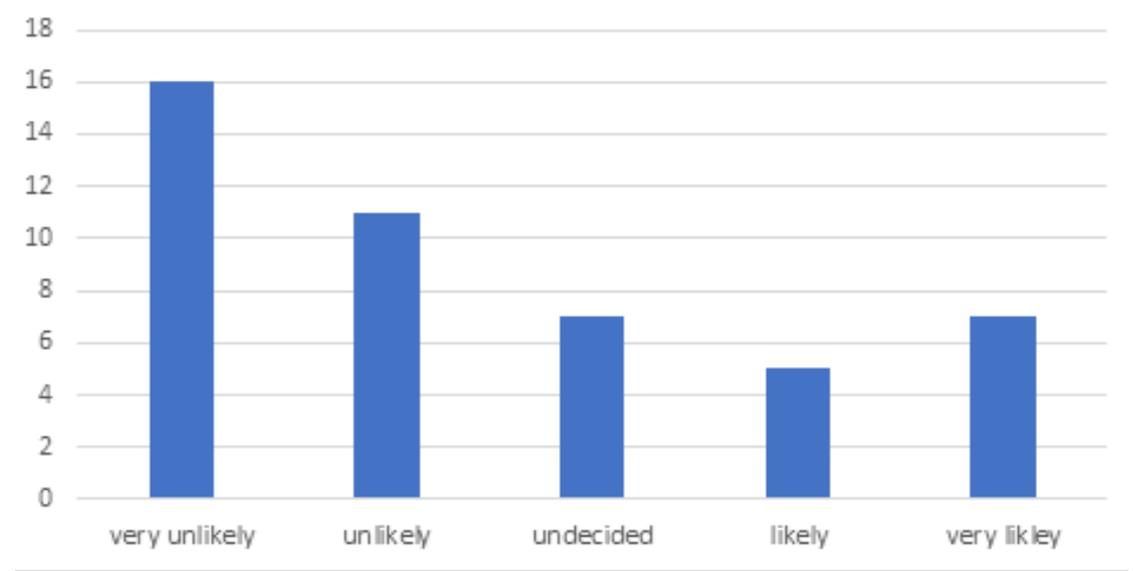
There was a total of 22 out of 26 respondents (85%) were vaccine hesitant (either undecided, unlikely or very unlikely) to take the vaccine. Those living on their own were more likely to show a higher level of representation in the category of undecided; seven out of 26 (27%) compared to seven out of 46 (15%) who lived with one or more people. There were only four participants living on their own (15%) who were likely or very likely to take the vaccine.

Living on My Own Likelihood of Taking a Vaccine N = 26



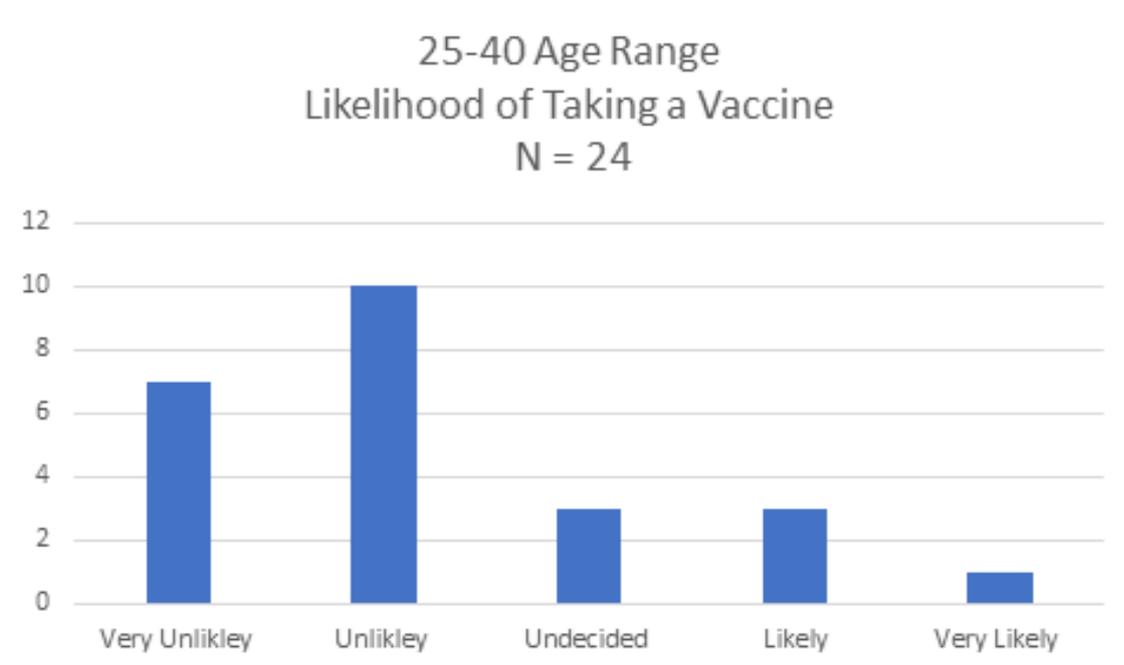
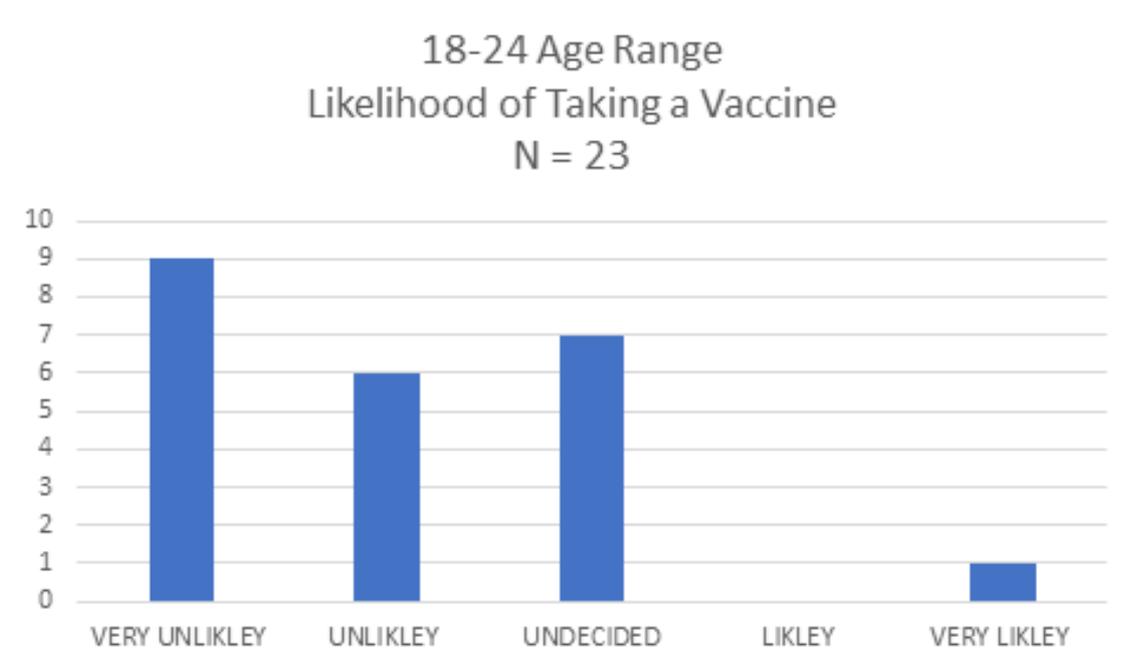
Of those living with one or more people, 34 out of 46 respondents (74%) were either undecided, unlikely or very unlikely to take the vaccine. There were 12 respondents (26%) who were likely or very likely to take the vaccine.

Living with One or More People Likelihood of Taking a Vaccine N = 46

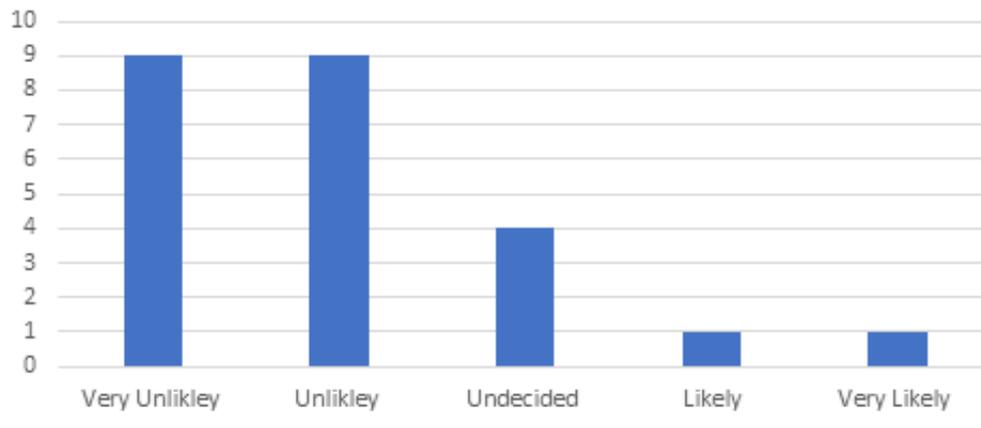


Age of Participants

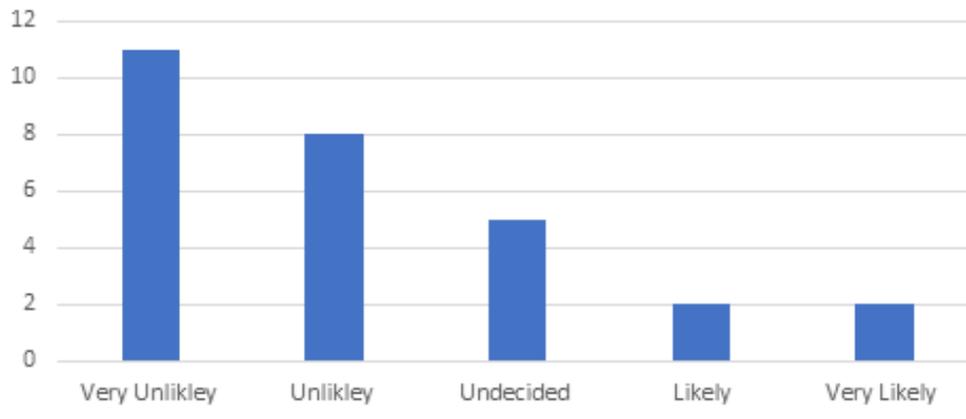
The 18 to 24 age range showed the highest level of vaccine hesitancy at 96%. The 25 to 40 age range were 83% vaccine hesitant with 17% vaccine positive. The 41 to 54 age range were 92% vaccine hesitant and 8% vaccine positive. The 55 to 64 age range had an 86 % vaccine hesitancy with 14% vaccine positive. As a standalone age range, the 80+ age range returned a 50/50 result between vaccine hesitance and vaccine positive but due to the low numbers within the 80+ category their responses have been merged with the 65 to 79 categories to create a 65+ age group. In the 65+ age group, 22% were likely or very likely to take a vaccine whilst 78% expressed vaccine hesitancy.



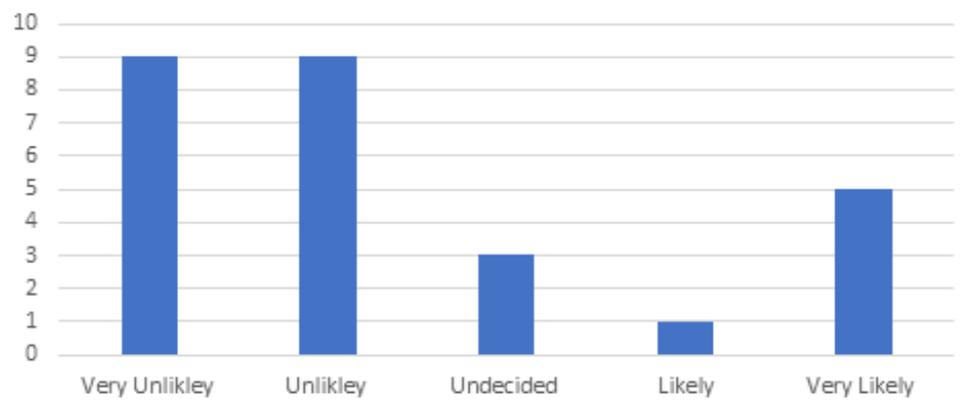
41-54 Age Range
Likelihood of Taking a Vaccine
N = 24



55-64 Age Range
Likelihood of Taking a Vaccine
N = 28



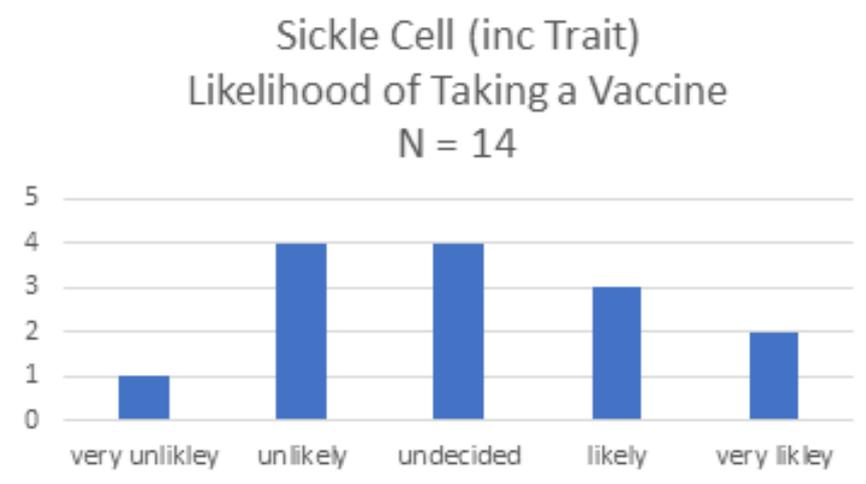
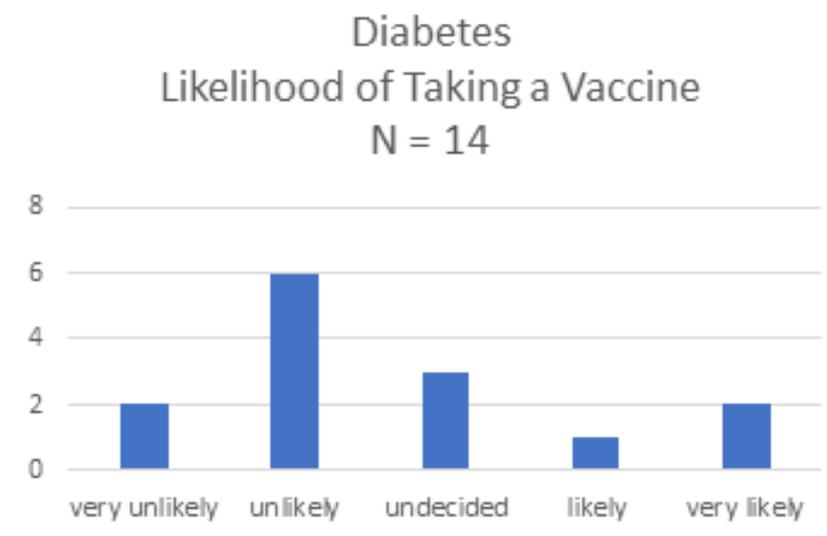
65+ Age Range
Likelihood of Taking a Vaccine
N = 27



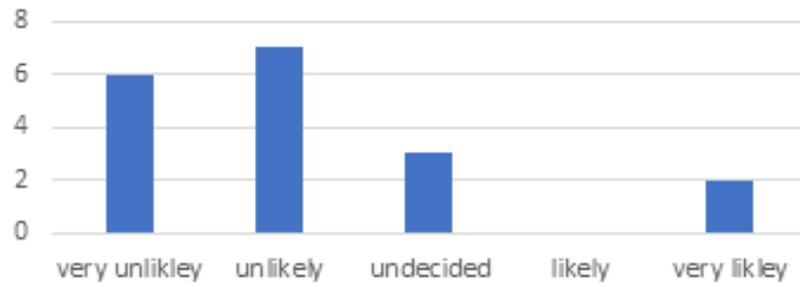
The pattern of hesitancy was the strongest amongst the younger age ranges however there was also a strong element of COVID-19 vaccine hesitancy across all the others age ranges too. Although the 41 to 54 age range is most likely to have a combination of caring duties and dependents, this group had the second highest level of hesitancy of all age ranges.

Health Conditions

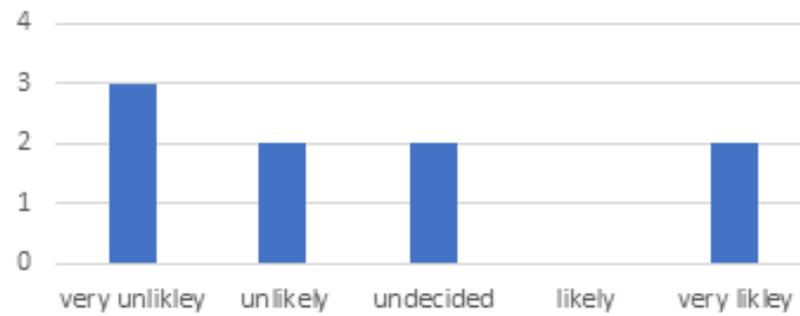
When we looked at COVID-19 vaccine hesitancy regarding the four most registered underlying health conditions - High Blood Pressure, Diabetes, Sickle Cell Anaemia (and trait) and Asthma/Respiratory conditions - we found that there was an overall pattern towards vaccine hesitancy, but the patterns differed by condition. Those reporting Sickle Cell had the highest level of undecided responses (29%) but also higher levels of likely or very likely responses for taking the vaccine (36%). When comparing this to other health conditions, the rates for likely or very likely to take the vaccine were 21% for those with Diabetes, 20% for those with Asthma/Respiratory conditions, and 11% for those with High Blood Pressure. Thus, those with High Blood Pressure were most vaccine hesitant when compared to the three other health conditions.



**High Blood Pressure
Likelihood of Taking a Vaccine
N = 18**



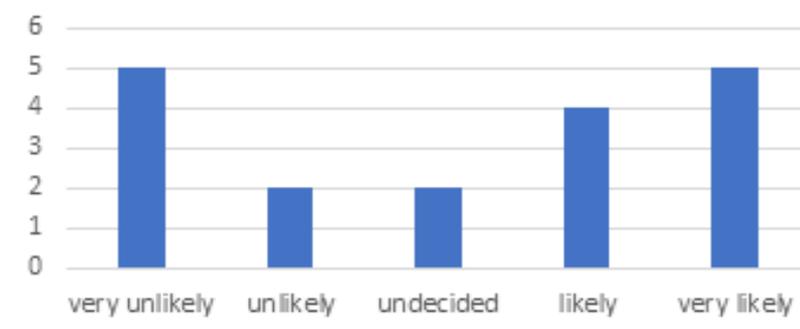
**Asthma/Respiratory Conditions
Likelihood of Taking a Vaccine
N = 10**

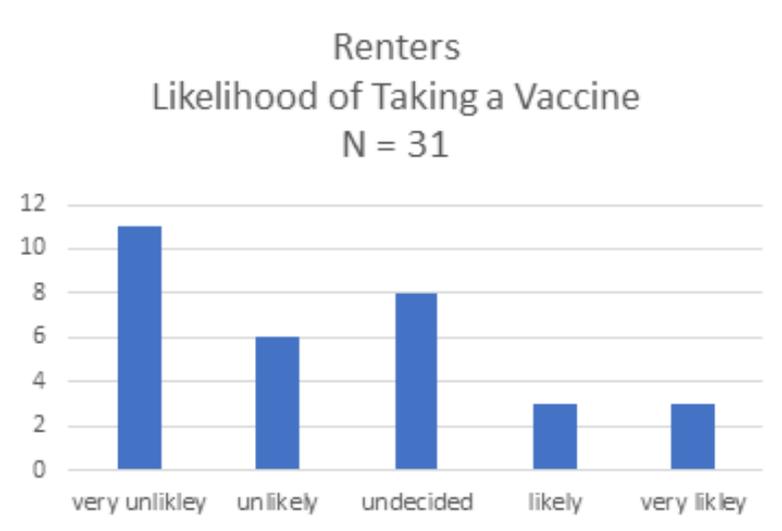


Housing Status

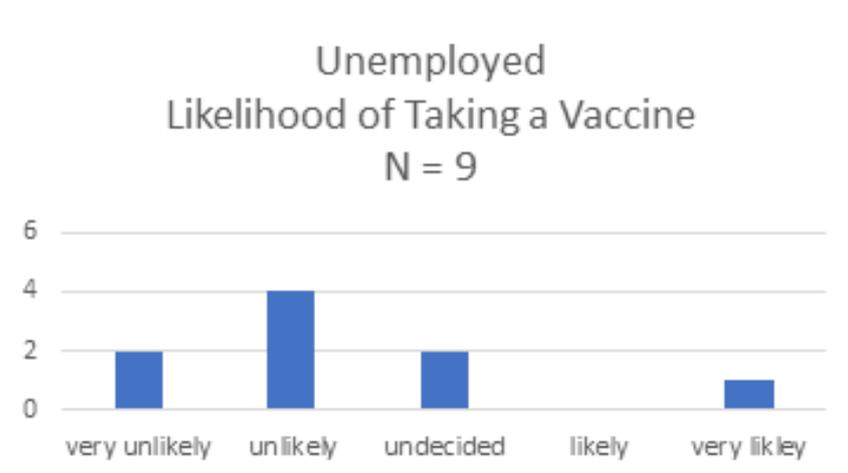
When looking to see if there were any differences in living arrangements, we found that those who owned their properties outright had an even 50/50 split between being vaccine hesitant and being vaccine positive. There was a total of 25 out of 31 renters (80%) who were vaccine hesitant. Of those renting, 26% were undecided compared to 11% of homeowners. This indicated that homeowners were more likely to take a vaccine than those renting.

**Owner Occupier No Mortgage
Likelihood of Taking a Vaccine
N = 18**



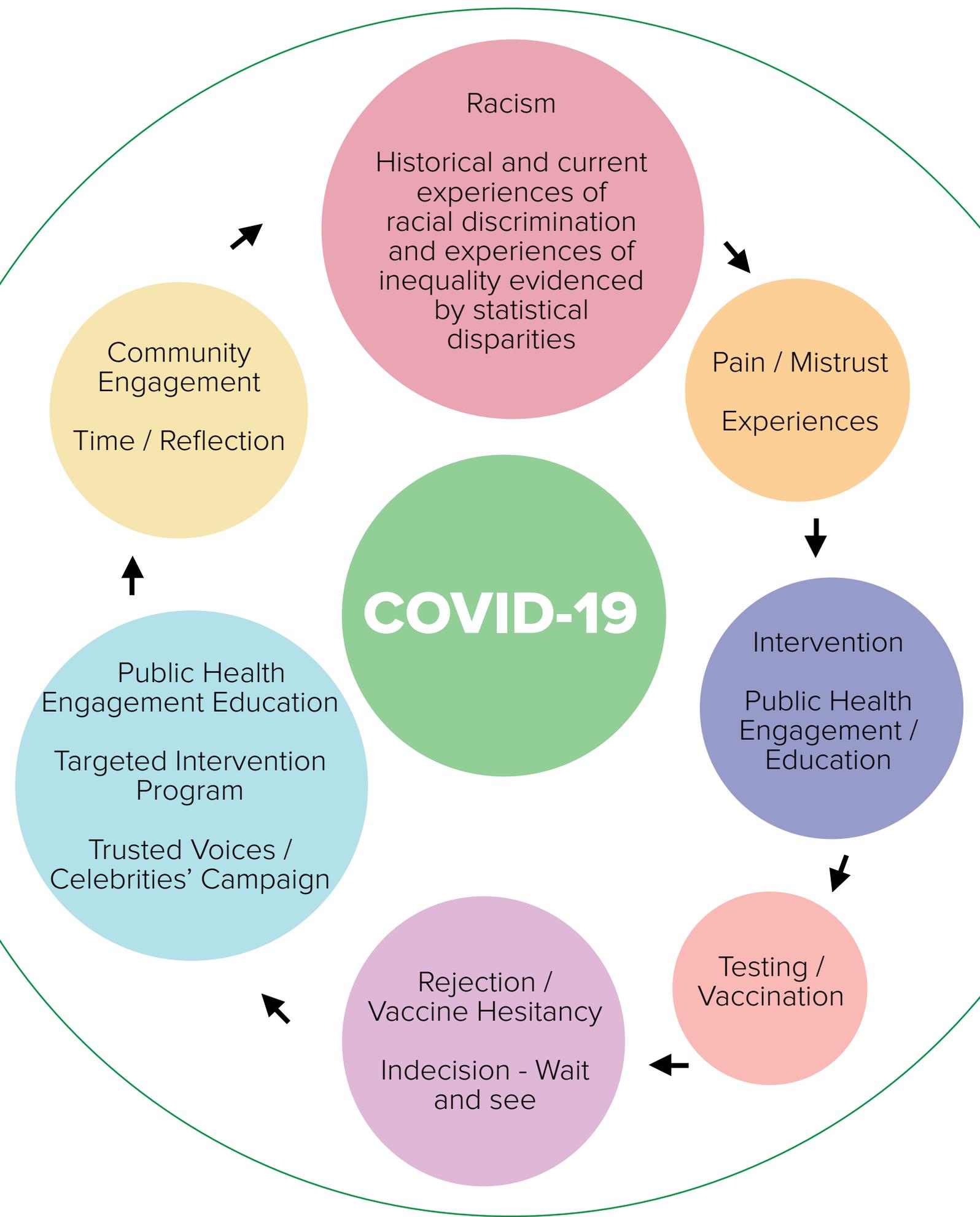


The sample showed that participants showed a higher-than-average level of unemployment and when we looked at the likelihood of people who were unemployed taking a vaccine, we found that vaccine hesitancy was still high with eight out of nine people being vaccine hesitant.



To vaccinate
or not . . .
**that is the
question**







Interview and Focus Groups Findings

The findings from the interviews and focus groups are presented in key themes. These are shown under headings which reflect the structure of the semi-structured questionnaire and focus group interview format. The themes are presented in the participants' own words and a selection of quotes from participants with similar viewpoints are shown to further illustrate the themes that emerged.

Being in lockdown: Thoughts and Feelings

We wanted to explore people's thoughts and feelings around COVID-19 and their experience of being in lockdown.

It wasn't clear what it was all about.

Some of the participants spoke of a lack of clarity and understanding when the lockdown was first announced:

“When it was announced to me it wasn't clear what it was all about, because I never in my life seen anything like that so you know, I was just surprised how it would look like but as time went by, that is when it became quite clear what lockdown is all about” (age range 41-54)

“I wasn't sure what to think to be honest, I just went through the motions... I didn't quite understand exactly what it was all about... I think it took me a while to really sink in how serious it was, but I think when all the shops shut and we were housebound and was told to stay at home and only to, you know, go out for exercise only, I realized it's very serious and started reading up on it” (age range 25-40)

The lockdown was well overdue.

Several participants spoke of anticipating the need for a national lockdown and being relieved about it being implemented by the government:

“My first thoughts was that the lockdown was well overdue due to the rising number of cases/deaths” (age range 18-24)

“My thought was that we need to do it to save lives and protect the NHS so I didn't have a problem with the lockdown” (age range 55-64)

“When I first thought there was going to be a lockdown I thought, to be honest I thought it was required because obviously the virus was getting out of hand” (age range 55-64)

I was shocked at national lockdown.

When asked about thoughts and feelings, many participants spoke of their initial shock:

“I was shocked at national lockdown but I wasn’t totally surprised, I did think something has to happen. I didn’t really think much of the impact it would have on our daily lives in regards to working and socializing, that realization came later” (age range 18-24)

“Having known all what was going on around the world in regards to COVID-19, I was still surprised that we were going to be locked down. It actually seemed surreal” (age unknown)

“I just felt like ‘is this actually for real are they being serious’ like he’s actually going to try and shut down the whole country and is it gonna work and for how long? So I didn’t know if it was actually a serious thing or not, you know, how serious was the actual pandemic to lock down the whole country” (age range 25-40)

I felt weary and frightened.

Some participants spoke about the worry and anxiety they experienced due to not knowing what to expect and concerns about the impact of being in a lockdown:

“I felt weary and frightened when I first heard the news and didn’t know what to expect” (age range 41-54)

“After about a month I started to feel levels of anxiety because I was just at home all the time, the idea of it sounded great but then when it came into play it wasn’t so great so I’ve been struggling from the start to be honest” (age range 25-40)

“As I was caring for a terminally ill relative at the time lockdown began, I was very worried about social distancing, not wanting to infect my sick relative, concerned about my relative contracting the virus, it was a very worrying time for me and my family. As a mother/grandmother I was also worried and concerned regarding the closure of universities, colleges and schools, how is the future generation going to learn and get an education” (age range 55-64)

There were additional worries expressed by individuals with underlying medical conditions, particularly in relation to accessing healthcare should this be needed and being able to complete essential activities such as shopping:

“I was worried about how I would function not doing the things I used to do like grocery shopping, going to my GP and being in hospital when I get a crisis or sickle cell pain” (age range 41-54)

“So, first thoughts and feelings was how am I gonna stay indoors when I quite rely on going out to receive medical care and the second one was being able to go shopping freely and comfortably without fretting too much” (age range 25-40)

“I think that there will be a lot of people who are scared and anxious about going into hospitals, because we’re hearing of so many people who go to the hospital and don’t come out” (age range 18-24)

Being Isolated and quarantined.

Many participants spoke of feeling isolated whilst being in lockdown due to the restrictions and lack of physical contact with family and friends:

“Being isolated and quarantined not being able to do things freely and able to receive as much support as I’d like to from family and friends” (age range 25-40)

“At times I do get a bit down just not being able to see family and friends” (age range 41-54)

“Isolation has been the low point. Not being able to be with family and friends” (age range 55-64)

“I would say probably the one that chimes the most of my experience has been isolation. It has been very difficult at times to give myself a mental boost or to keep myself up” (age range 18-24)

Talking on the phone isn’t the same.

Whilst most participants spoke of maintaining contact with family and friends via telephone or video call, many missed the physical, face to face contact:

“I feel quite sad not spending time with my family members who I normally visit on a regularly basis. Talking on the phone isn’t the same” (age range 41-54)

“Sometimes you wish you could go to a family or friends house, just see them face to face instead of seeing over the phone” (age range 25-40)

“Isolation stands out precisely because you know as humans, we need to visit other people, we need to socialize, all that was cut out. So, you only talk to people on the phone that’s not enough” (age range 41-55)

Closer to my family.

A small number of participants spoke of feeling closer to family and friends as a result of being in lockdown due to increased contact during this period:

“It has made me speak to them more through WhatsApp video call, so you could say lockdown has made me closer to my family” (age range 41-54)

“I live with my mom, it has kind of made our relationship stronger... She’s got to know me and stuff, so there has been positives for me and it hasn’t all been bad” (age range 25-40)

“We did notice that I’m speaking to more people over FaceTime and on the phone than before” (age range 55-64)

Information Sources and key messages

We wanted to understand where people were going for their information around COVID-19 and the lockdown; to find out if it was mainstream or social media and which sources they relied on.

Mainly the mainstream media news and the covid update.

Most participants obtained information about COVID-19 from television and radio, particularly mainstream news and government updates:

“Mainly the mainstream media news and the covid update, so my source of information was mainly from that program and, you know, you had the Prime Minister and his members stood at pedestals informing us the public of what the statistics were” (age range 18-24)

“I relied on mainstream news and local council guidelines” (age range 55-64)

“There’s plenty of guidance coming from the daily news briefings when they used to have them and directed you to obviously the gov site and if you wanted more detail about guidance and specific lockdown rules and also any lockdown or restrictions in certain areas, and so plenty of guidance there” (age range 55-64)

“My main sources would be the news in the morning” (age range 18-24)

Letters or texts from the government.

Some participants said they were getting information directly from the government or local authority:

“I get the letters or texts from the government; I think those are quite straightforward and probably easier to follow and I go by those” (age range 25-40)

“Leaflets dropped by the city council as well and they on the whole are quite sensible legitimate and practical steps that we should adhere to and one has to say yes that’s very good” (age range 65-79)

“I’ve been getting information mostly from the government sites” (age range 25-40)

The NHS’s guidance and support has been good.

Participants were very supportive of the role that the NHS has played during the pandemic, most also obtained information directly from the NHS and this was considered helpful:

“The NHS’s guidance and support has been good because I have a good understanding of what needs to be done to get out of this situation” (age 18-24)

“The NHS information that was coming through seems to be fairly reliable based on what was happening within hospital for me, so I tended to rely a lot on the NHS information and guidelines we were getting there” (age range 55-64)

“If you go on the NHS website you get bullet points of what to do what not to do, etc, and so that’s clear cut... yeah I’m quite confident with the guidance that we’ve received from the NHS” (age range 25-40)

“We have practical steps that have been sent to us through our GP surgery” (age range 65-70)

A minority were critical of the NHS and the local authority:

“For the NHS I don’t think they really gave us any guidance and I think they just went up there based on what the government was saying, and I don’t think there was much guidance there. Nothing for the local government, I don’t even know what they did during this pandemic really around here and yeah but no idea what they did” (age range 18-24)

“There was no support really from local government... They were almost fighting for their own positions” (age range 55-64)

Third sector

There were participants who obtained information from third sector agencies in addition to other sources:

“Apart from the letters from the government and the local council, I had third sector sickle cell charities that would inform me... in particular Sandwell West Bromwich Oscar that would inform me” (age range 55-64)

“I’ve been checking on this from the government sites, I’ve placed calls to Oscar Sandwell once in a while, I’ve chatted with the director there... so um yeah I’ve been getting information mostly from the government sites, I check updates and see what is on then from my employers, from OSCAR Sandwell, from friends and family and even the news” (age range 25-40)

“Church, we have a newsletter every week and we get news and information about the guidelines and what we’re supposed to be doing but that’s something that comes through every week, it just coincides with what government guidelines, what is sent out to me anyway” (age range 55-64)

“There has been information via Shane to the African Caribbean Centre and that’s been very, very useful and very helpful” (age range 55-64)

Some spoke of their appreciation of third sector agencies being available to help make sense of information:

“I listen to what the news is saying and then try and make some sort of sense or might have communication with third sector sickle cell charity or an individual to see what their thoughts about it is” (age range 55-64)

“From what I have seen and heard from other people, I think, churches and like faith-based communities really have stepped up and have been supporting people that they come into contact with, and I think there’s been a lot of reliance on my community and the community and charities within the community and for information to break down the information that’s being said” (age unknown)

A number of participants preferred to obtain information from family and friends. Some participants felt that information obtained from family and friends was more understandable and reliable:

“Speaking to my family is the main way I have been finding out about things” (age range 41-54)

“I feel the guidance given by my family members has been good which has allowed me to stay positive during this pandemic” (age range 18-24)

“The news is confusing and understanding everything, I mainly relied on my brothers telling me what they were on about and relay it in layman’s terms and just keep me up to speed with everything” (age range 25-40)

“Friends via telephone communication, internet or watching the news... Listening to friends has been the most reliable, they keep me updated and also I am able to have a conversation about things” (age range 41-54)

We’ve gotten a lot of information from the internet and social media. Most participants had received information from social media in addition to other information outlets:

“We’ve gotten a lot of information from the internet and social media, YouTube and there’s a lot of false information but there’s a lot of really good information” (age range 25-40)

“I mainly received information about covid 19 through social media sites such as Twitter, Instagram and WhatsApp. After that I would say I got the most information from mainstream news networks such as the BBC, ITV, and Channel 4 (age range 18-24)

“I did see a couple of things on Facebook and WhatsApp but those were full of conspiracy theories which I didn’t really take much note of” (age range 41-54)

Reliability of Information

We wanted to find out which sources of information were considered most reliable by participants.

The government website and medical journals.

Several participants considered official websites the most reliable source of information. This included government websites, journals and the NHS:

“The most reliable I would say is the government website and medical journals because they give the full report of everything, it’s very detailed” (age range 25-40)

“Most reliable - medical professionals online on YouTube, reliable scientists” (age range 41-54)

“There is SAGE and the scientists and the healthcare professionals, they are more in tune and more accurate with the advice giving and I’d rather listen to what the scientists has to say about this particular virus and how deadly it is and what we need to do to protect ourselves” (age range 65-79)

“I relied on government sources but the original source... I would always go to the NHS website as soon as that information was published. I shared that with my WhatsApp group so I always go to the original source because press conferences and all these things that you see on Twitter, they’re just a very small part of the message and it’s just the way my brain works. I want to understand the whole message” (age range 55-64)

The news outlets.

Additionally, many participants considered the mainstream media a reliable source of information:

“The news outlets, CNN online, Sky News, ITV, BBC ... because they will quote something about their sources, they’re usually scientific as well” (age range 55-64)

“I rely more so on traditional outlets such as BBC, Sky News, for what I believe to be a more rounded view as to what’s going on the virus” (age range 18-24)

“Very much the mainstream media and the statistics and the research that come out the Cobra meetings and the daily press conferences, I very much rely on that for information to digest when it comes to COVID 19. I tend to stay away from what people are saying in my neighbourhood only because there are a lot of ill-informed views, a lot of misinformation which has been put out there to the masses to consume, so I tend to rely on mentioned media for my news when it comes to the virus” (age range 18-24)

“At least with mainstream media networks they have to fact check information before sharing it with the public but on social media anybody could share misleading or fabricated information without the need to check if what they are sharing is actually true, which leads to a lot people becoming misinformed” (age range 18-24)

New Style Radio aired an imbalanced show about COVID-19. This prompted an investigation by the media regulator OFCOM. A complaint was upheld and the radio station was ordered to address the imbalance aired on the previous programme. The follow up programme was then made referencing NHS data and other official Government data. The station arranged for this to be done 2 weeks later with a panel including: Dr Justin Varney - Director of Public Health / Birmingham City Council, Councillor Paulette Hamilton - Cabinet Minister for Health and Tony Kelly - Diabetes Strategic Patient Partner - NHS Birmingham & Solihull Clinical Commissioning Group.

Ofcom adjudication on Newstyle Radio

https://www.ofcom.org.uk/__data/assets/pdf_file/0020/220835/Decision-on-Further-Sanction-Afro-Caribbean-Millennium-Centre-ACMC.pdf

I didn't rely on social media for my information.

Many participants did not consider any particular information source as completely reliable and social media was repeatedly described as the least reliable due to the potential for misinformation and not being able to verify information:

"I didn't rely on social media for my information, but it was always there if that makes sense... I'm on Facebook so you've got all kinds of information or misinformation going around on social media. So it's just there in your face even if you don't want it, even if you're not going on there to look for it"

"A lot of the times I find Twitter is for other people's opinion... I'm a very visual person and seeing the evidence in front of me is very helpful"

"I would rather listen to the news than read anything on social media because social media gives false information" (age unknown)

"A lot of the information you don't know if it's accurate that comes on social media and the information that you do think is accurate is generally backed up by the mainstream news or mainstream media and so that's what I went by, so I thought well if it's not on the mainstream news then it's fake news or it's been interpreted wrong and someone's put it out there on social media" (age range 25-40)

There are some very strange conspiracy theories.

Some participants commented on the conspiracy theories they have come across on social media:

"The least reliable is probably Facebook because there are some very strange conspiracy theories going on Facebook and on Twitter but it depends on who you follow on Twitter" (age range 55-64)

"Social media was the most unreliable source because there is a lot of confusion, a lot of controversies a lot of theories and people saying things" (age range 25-40)

“The least place that I think had suitable information was like WhatsApp messages that people would send in groups... especially like the WhatsApp ones that had videos of certain people saying certain stuff, I think that information was not trustworthy at all” (age unknown)

“I’m not into the conspiracy theories at all and the fake and false information. People need to go to the tried and tested websites like Birmingham City Council, Sandwell council, Public Health England, National Health Service and there are other COVID-19 government approved websites that they need to go to for accurate factual and concrete information. Ones that will lead them astray and give them a false sense of security that there’s nothing, come on, look how many people have died... This isn’t make believe or, oh, it’s to do with the 5G and the microwaves and the radiation, absolute garbage, rubbish, nonsense, and we need to dispel that myth and get people to understand the severity of the situation which we are facing, this pandemic is worldwide, it’s not just Britain” (age range 65-79)

I don’t always believe what I hear on the news.

Although most participants obtained information from the mainstream news, many participants also expressed concerns about the trustworthiness and reliability of information from such information sources:

“I don’t always believe what I hear on the news” (age unknown)

“I have found the news the least reliable because of the inconsistent information. They say one thing and then say another” (age range 55-64)

“I watched less television or tell-lie-vision whichever one you want to call it because I noticed that the media seem to be putting a lot of fear into people so I watched less TV” (age range 41-54)

“I know how the news only gives you what they want to give you, they don’t give you the full story so I don’t always believe what I hear on the news” (age range 25-40)

There was no detail.

Several participants spoke about the lack of detail in the information they were given:

“There was no detail or concise information of what covid is other than that it is a virus, or some people say disease, that people with my health condition are more likely to catch and the consequences would be death” (age range 55-64)

“When they do their daily briefing... on the radio we only get the first bit when they’re doing all the charts and stuff... and then they spend the next 20 minutes just repeating what we’ve just heard the Prime Minister say... I’d like to know the information that’s being shared in the charts and stuff... so I find that annoying because I don’t get the background to why they say we’re bringing in this change... the radio just cuts off at that point and I don’t know why they do that I find that quite annoying” (age range 55-64)

“I want them to come with figures, I want them to tell me how many Black people are in the country and how many Black people have died, then you can tell me that we’re more likely and we’re dying at a higher rate than anybody else” (age range 55-64)

I always look for the evidence.

Several participants spoke of the need to see the evidence when determining the reliability of information:

“Being somebody that has gone to university and studied I always look for the evidence and social media wasn’t providing me with evidence, it was just giving me people’s views that were unqualified for the most part” (age range 55-64)

“Anyone can really just say anything on social media, if I was to see something on social media I’d type into Google and try and find a better source” (age range 18-24)

“You just have to use your own initiative... there’s so much rumours going around, deciphering from all the noise really to find out what’s real” (age range 25-40)

“A lot of people post different views and it can be a bit difficult to get a clear understanding of what the facts are and the truth is so certainly I do tend to take it with a pinch of salt what things people are saying on Facebook and Twitter” (age range 18-24)

I like to research stuff myself.

When discussing the reliability of information, many participants said they like to do their own research to help determine the facts:

“I like to research stuff myself. I would say Google because it’s what’s out there in the public and, you know, sometimes we ourselves need much more than, you know, find more into what’s just been given on the news or said on the radio because it’s just a brief thing that is said on the radio and stuff so when you search more on Google and, you know, you see extended versions of things and what’s happening and the reason behind it” (age range 25-40)

“I did my own research via web research - found information on Google”
(age range 41-54)

“I tend to do research myself because I don’t take what the NHS tells me as gospel as well” (age range 55-64)

“I kind of pick and choose from different pieces so, for example, if I watch something on Good Morning Britain (ITV) and they’re talking about the virus... then I research it for myself online” (age range 25-40)

You can be overwhelmed with information.

Participants spoke of becoming overwhelmed with information at times. As a result, some decided to limit the intake of information for their own wellbeing, and some decided to switch off completely.

“The more information is coming out, the more confusing it’s making things to me and you can be overwhelmed with information left right and centre and a lot of it was negative information. After a while you have to shut out some of that negativity for your own health and wellbeing, your own mental health and wellbeing” (age range 55-64)

“I try to be more in control of the intake of information because I chose to actually go on my phone and look at it that way rather than be inundated from the news and people and even the internet in terms of social media, there’s loads of talk on it there, so yeah you kind of have to just take it into your own hands just for your own mental health” (age range 25-40)

“To begin with, I stayed up to date with the latest updates – this was all super new and it was important that I listened to the people in charge. However, the more I listened the more I got annoyed at how they would tell us one thing and then tell us another, I also do not believe it is healthy for us to every day hear about how many people have died. It’s not normal for us to be hearing that every day” (age range 25-40)

“That’s all we hear about you know you turn on the TV it’s covid... the radio it’s covid... that’s all people hear and I don’t know if that’s a positive thing you know, not saying you shouldn’t report it but there’s other things going on in the world but if you just tell people nothing but covid in my opinion a couple of things can happen, they become paranoid or they can switch off... you’re overloading people... it’s just too much it’s just too much you know, people have to have something positive to look forward to” (age range 55-64)

For some, constant exposure was too much, to the point that people stopped listening to the news:

“I have steered clear of the news as I don’t think it is healthy to be told everyday how many people are dying. I watch the news and expect the media to provide us with hope and direction but the news they show injects fear into us” (age range 25-40)

Guidance and Support

We wanted to know how participants perceived guidance and support during the COVID-19 pandemic and lockdown:

It’s just very confusing.

Most participants considered the guidance and support from government to have been confusing:

“It’s not consistent when it comes to the news on COVID-19 and how to take care of yourself or how to follow the lockdown guidance and stuff it’s not consistent, you don’t

know if we should stay home or if you should go to work, you don't know if you should go to visit someone or someone coming to visit you it's just very confusing" (age range 41-54)

"Some of the information that was given by the Prime Minister was not straight up, it's confusing so one has to use their own imagination and use their own brain to think for themselves" (age range 80+)

"The average Joe public is still having a problem getting through the mixed messages that the government is constantly putting out" (age range 65-79)

"You know what was confusing is like okay can go out and mix in a pub, but with the lockdown you can't meet your own family... to me that wasn't quite logical" (age range 55-64)

There was also confusion amongst vulnerable groups, those with school aged children and those living in multi-generational households:

"Well it was very confusing and especially my household where we're all vulnerable, we're all told to shield in the first lockdown and the second is quite confusing because my daughter was supposed to go to school, yet me and my husband was supposed to shield so how is my daughter going to school within a bubble of 30 strangers around other people who we don't know they've been around but for her to come back to us seemed like it totally defeats the object of what it's supposed to do so that was very confusing and ridiculous to me" (age range 25-40)

"I think it was more of the worry, because my mom is high risk and it was kind of like because I was still going to work, then I was at risk of getting it from there and then bringing it home to her... that for me I would say was probably the most stressful thing of this whole lockdown" (age range 18-24)

"My daughter is a student nurse and she's within hospitals... at the time I think I was more concerned about my daughter having to go into the hospitals and what she would be bringing home... She had PPE while she was in the ward but when she came home there was nothing for me, there's nothing for my son. I would put her clothes in the washing machine. Each night she came home from the covid ward I wasn't told to isolate, I wasn't given any guidance" (age range 41-54)

They didn't really know what they were doing.

Some participants felt as though the government did not know what they were doing and that issues arose because of this:

"I think it just got really out of hand because they didn't really know what they were doing so they were trying to tell us to stay at home but realized that they couldn't, it's not that Black and white so then they brought in all of these other extra rules and that just made it all quite confusing" (age range 18-24)

"I think that the guidance and support from the central government has been poor as it has never been understandable. I feel like there was a lot of misinformation and a lack of accountability/responsibility by those in power to accept that they have been negligent in failing to introduce basic restrictions that potentially could have made a big difference to

how the virus has spread e.g. closing the borders” (age range 18-24)

“The government didn’t know what they were saying a lot of the time, one moment you can do this, you can’t do this, you could go here you couldn’t go there” (age range 41-54)

“In terms of the advice from the government. Again, I think it was wishy washy. It could have been more decisive. I don’t think the government was decisive enough in a decision making” (age range 55-64)

Inconsistency in the approach.

Many participants spoke about inconsistency and contradiction in information and guidance:

“That didn’t help when they kept on changing the rules because in the first lockdown we weren’t supposed to leave our home at all. It’s an inconsistency in the approach, which is not helping people” (age range 65-79)

“Information about covid has been contradictory which is not useful. I do not believe in a lot of the scare mongering and go by statistical information... I have very little faith in guidance as information is contradictory” (age range 55-64)

“I have felt angry at how contradictory the rules have been, especially in the sports industry – Elite and professional sports can continue however non-elite and recreational cannot, I don’t think it makes sense and it triggers the view that societal classes get treated differently” (age range 25-40)

“At times it’s been quite ambiguous. When I say ambiguous, I mean they say don’t do something or we need to keep the R number down and this is how you go about it, but for example when they said people shouldn’t mingle and they still left the pubs open and they entertain you know where people can gather and mingle and get together and have a large crowd, those things, those places were still open. You know you can’t want people not to mingle but then you’ve got a lot of places where people will socialize in large numbers still functioning” (age range 55-64)

They keep changing the rules.

Similarly, participants spoke of information and guidance changing too frequently, which can contribute to confusion, understanding and adherence of the rules:

“The fact they keep changing the rules means that they are losing value in what they are saying” (age range 55-64)

“The central government advice and guidance is confusing because of how quickly they change rules and restrictions” (age range 18-24)

“I think that guidance can be confusing, there can be a lot of mixed messaging and if you’re not on top of stuff, you know, in terms of keeping up to date with the various briefings, particularly over a couple of weeks the guidance change... so that can lead you to sort of act against the rules or the guidance if you’re not keeping on top of things

on a daily basis, or at least on a weekly basis... particularly with the tier situations and stuff... If you don't keep on top of the information, it can get a bit blurred" (age range 55-64)

Everything was like last minute.

Several participants spoke about quick changes to guidelines which made it difficult to follow and keep up with, contributing to feelings of confusion:

"Mixed messages about the so-called guidance from the government and the way they did it, everything was like last minute, you'd be told today it comes into effect tomorrow which didn't give people time to plan or you know make arrangements or adjust. And you know you kind of heard rumours first and then the government would say something and then it will come into force. When we had the lockdowns, you were literally like told from tomorrow we're locking down" (age range 55-64)

"No one really understands the full policies and policies are being changed as we speak... so if they're changing policies like that there's a lot of policies which people ain't gonna be able to grasp" (age range 18-24)

"The schools were a very good example, when schools are asked to open and then the following day are to close, when people are told that public transport is safe and then public transport isn't safe, when people are told to lockdown and not locked down when it comes to Christmas... it's all confusing" (age range 55-64)

There was a feeling that the government were not adhering to their own message particularly the restrictions on movement and social distancing:

"I felt that there was one rule for those in government or those in particular positions of influence and another rule for everybody else but because people like Mr Cummings and you know, Michael Gove and you know people like that were found not to be keeping the rules or sticking to the rules, but nothing happened they didn't pay a price" (age range 55-64)

I chose to pick out what made sense to me.

Participants spoke of making their own decisions, or anticipating that others may not adhere to the guidance as a result of the ambiguity and confusion of government guidance, rules and restrictions:

"I don't think the government helped a lot with their information because I felt they chopped and changed the rules, restrictions, information they were giving out to us, so I think for myself. I chose to pick out what made sense to me and ignore what didn't make sense to me" (age range 55-64)

"I'm so confused now I just think for myself and work things out for myself now" (age unknown)

The UK government really tried.

Several participants displayed some empathy with the government and believed the government had tried to manage the situation as well as they could with the information they had at that time:

“It’s a shock to the whole world, nobody had experienced it before so even the government were thrown off balance, they were confused they don’t know the best approach to it... I will say that the UK government really tried in terms of the information that was given out even though it’s confusing at some points but personally I wouldn’t really blame them because it’s a situation nobody had experienced before and sometimes as humans when we are faced with challenges we’ve not seen, we try different approaches to tackle them and if we say that one is not working we want to move to the next one and try other things” (age range 25-40)

“I think the support and guidance is really, really good, and you know we are living through unprecedented times, very challenging times that nobody could have foreseen so we’ll kind of walk you through this blind to a certain degree, we haven’t had a template to work up before when it comes to a pandemic on this scale and of this nature, so I’ve been reasonably happy with the level of guidance and advice I’ve been given from central government, from charities, from religious institutions” (age range 18-24)

“The government has its part to play because they need to get the information out there but I feel sorry for them in some ways... It’s a changing fluid situation where it’s not static, so by the time one bit of advice comes out something’s changed” (age range 65-79)

“I think that the government has really done their best to try to give the public as much information as they could and you know the pandemic here it spread rapidly throughout the country, so it was a case of government having to redirect resources to get guidance in place and change procedures and processes. I think the government really did try to do their best and to deliver simple, straightforward messages to the public whilst trying to protect those who are the most vulnerable and in need” (age range 18-24)

Support given by charity community groups.

A number of participants said they had received support from various organisations including the local Sickle Cell Centre, the African Caribbean Resource Centre and Churches. Some relied on these services for access to essential items:

“I think the guidance and support given by charity community groups throughout the pandemic has been fantastic” (age range 18-24)

“I’ve quite a bit of support from my local church and I had quite a bit of support from OSCAR Birmingham” (age range 41-54)

“I feel lucky that I have the Kuumba Centre and other organizations, some people don’t have that” (age range 41-54)

Some participants spoke about specific facilities and services they have accessed from third sector agencies:

“Church has been doing health seminars and so that’s been more detailed and more personal than obviously the government and NHS is because they have doctors that will come and talk to people and give people guidance about it” (age range 25-40)

“I’d like to say that the people that have helped me the most during the covid scare has been the local sickle cell centre and the pastor rang me up and said that special prayers are being said for me, that cheered me up. I rang up the sickle cell centre and could get help with food boxes that was great” (age range 18-24)

“My son is a member of the boy’s brigade with the local church. Obviously, since lockdown he hasn’t been but they have kept in contact with me, they pop down to my house and post little worksheets for him to do and little leaflets like giving us information on what’s going to happen in the future, or just general words of encouragement and support so that’s been good” (age range 25-40)

“I recently had support from the West Bromwich African Caribbean Resource Centre... they’ve lent me a tablet... so I can connect with people and carry on with my job searching” (age range 55-64)

“My support groups and third sector sickle cell charity and NHS specialist treatment centre project they helped as well... the food bank run from my church they will donate stuff to me... my local community centre, they also ring around every week and see if I need anything and have provided food parcels as well” (age range 25-40)

Measures taken

We wanted to understand which measures participants felt were most effective in reducing the spread of the virus and which of those they considered least effective.

Cover your nose, keep distance, wash your hands.

All participants were familiar with the key messages of regularly hand washing, socially distancing, wearing a face mask, limiting social gatherings, tier systems and track and trace.

Many considered messages around sanitation and hygiene effective for the population in general:

“The information out there cover your nose, keep distance, wash your hands, those ones have been helpful” (age range 25-40)

“Maybe sanitization has been probably the most effective” (age range 25-40)



Lard me caaarn tek no more!

(Caribbean saying when things become too much)

“I think the most effective has been the introduction of social distancing, PPE and encouraging regular hand washing” (age range 18-24)

“I think the most effective is actually putting the sanitizers out and actually seeing people actually use them, because even before covid a lot of people weren’t washing their hands and sanitising. I think knowing now that people are actually taking more of a lead in washing their hands and sanitizing and being clean about covering their mouths when they’re coughing, they should be doing that anyway but I’m glad that now people are actually realizing you know this is how infection spreads” (age range 25-40)

The most effective measure seems to be the lockdown.

Most participants considered the national lockdown the most effective government measure in slowing down the spread of the virus. Additionally, some participants believed that having one set of rules and guidance that applied to all was helpful:

“In my opinion the most effective measures have been the national lockdown measures because it is easier for people to follow the rules because everybody has the same restrictions and guidelines” (age range 18-24)

“I do believe it slows down the spread of the virus and you know, after a month or so you see the difference, it seems that’s what they’re showing anyway, so you know I’m happy to do that” (age range 25-40)

Many participants believed the first lockdown had been the most effective measure and that people were no longer adhering to the rules and guidance:

“I think the first one was clear and concise and everybody kind of stuck to that because we all understood and then there was a clapping of the NHS and it was like the whole country was like working together, but I’ve seen things since he eased it, I think a lot of people are just doing what they want to do... because even on the roads now, the roads are still busy compared to how it was the March” (age unknown)

“When you had the first lockdown and when the schools were closed, shops were closed, non-essential shops were closed, we were told to stay at home, only come out for exercise, that was the most effective without a shadow of a doubt and I think since then we’ve tried different things... and it hasn’t really been as effective as the lockdown” (age range 55-64)

Some participants linked reduced adherence to subsequent lockdowns to the first lockdown being lifted too soon, there being different rules in place and more businesses and services remaining open, such as schools and some shops:

“I think the initial first lockdown was good because everybody was locked down and it was like really strict and people were adhering to it but I kind of think that that was lifted too soon... subsequent lockdowns after that haven’t been beneficial in my opinion because nobody’s listening to the rules, the government isn’t making stern decisions they keep going back and forth back and forth, so people have lost confidence in them” (age range 18-24)

“I would want us to go really back to the first lock down that was a true lockdown. This one I see too many cars out there and too many things happening. And so this is not the lockdown that we had in mind, that was a proper one and everything was shut down and people really had to stay at home and in some countries where the virus is almost non-existent, they went for the full proper lockdown” (age range 65-79)

“I would think that putting us in a strict lockdown would have been the most effective but the way they have chopped and changed the rules – it has just made things worse. For example, we locked down and once that was finished pubs and restaurants offered a 50% eat out to help out scheme that encouraged us to socialize and spend money, when weeks before that we wasn’t allowed to be more than 2m close to someone” (age range 25-40)

I didn’t really like the tier idea.

Tiers were introduced in October 2020 in response to the regional differences in hospital admissions.

Most participants said they disliked the tier system. This was linked to confusion around decision making and how tiers were used, particularly when placing boroughs in higher tiers with increased restrictions. Problems with enforcing such restrictions was also mentioned. The national lockdown or a blanket approach was considered preferable:

“I didn’t really like the tier idea... it was causing a lot of divide between areas and the discrepancies between areas weren’t really relevant some of the times... people are crossing from area to area so it makes much more sense having a national tier so either everyone’s in lockdown or either everyone’s in tier two type or everyone’s in a tier three” (age range 18-24)

“Keep the messages clear and digestible for the population, the tier system I thought was a misgauged failure. It’s very ambiguous as to what the rules were in certain locations, it’s impossible to police... So for me national lockdowns went very, very well it’s clear that they are effective, the tier system not so much and I do hope that policymakers won’t adopt that system again when moving forward” (age range 18-24)

“The tier system was a waste of time because nobody was policing people, some people would travel from Birmingham to London to eat out or vice versa, so that was a waste of time” (age range 25-40)

“I feel the tier system has been the least effective because it’s very difficult to maintain differing restrictions throughout the country and it’s very difficult to follow with the government adding new tiers in the middle of tier system restrictions” (age range 18-24)

A few participants stated that they did not like the tier system as they felt the tiers that areas were placed in were based on economic decisions:

“I didn’t like it because it felt more like it could be economical stuff more than the safety” (age range 55-64)

“I think what the tier system highlighted was a hierarchy in areas, for example, you have places like London that wouldn’t be on the same tier as say Manchester. You know, working class areas were locked down far more than London, London being more cosmopolitan than anywhere else and so, again, I think there should be a blanket approach so that nobody’s questioning why them and not us right and vice versa (age range 55-64)

I think track and trace is effective.

NB (Although the official term was test and trace it was quickly translated into track and trace) There were a small number of participants who considered the track and trace system effective:

“I think track and trace is effective especially earlier in the year when people actually were mingling” (age range 18-24)

“If you can track people, identify people who got the covid virus then they can isolate to prevent that spreading so that can be quite effective if worked correctly” (age range 55-64)

“I think it’s making a good contribution I think it’s a useful tool” (age range 18-24)

I did not see how track and trace would work.

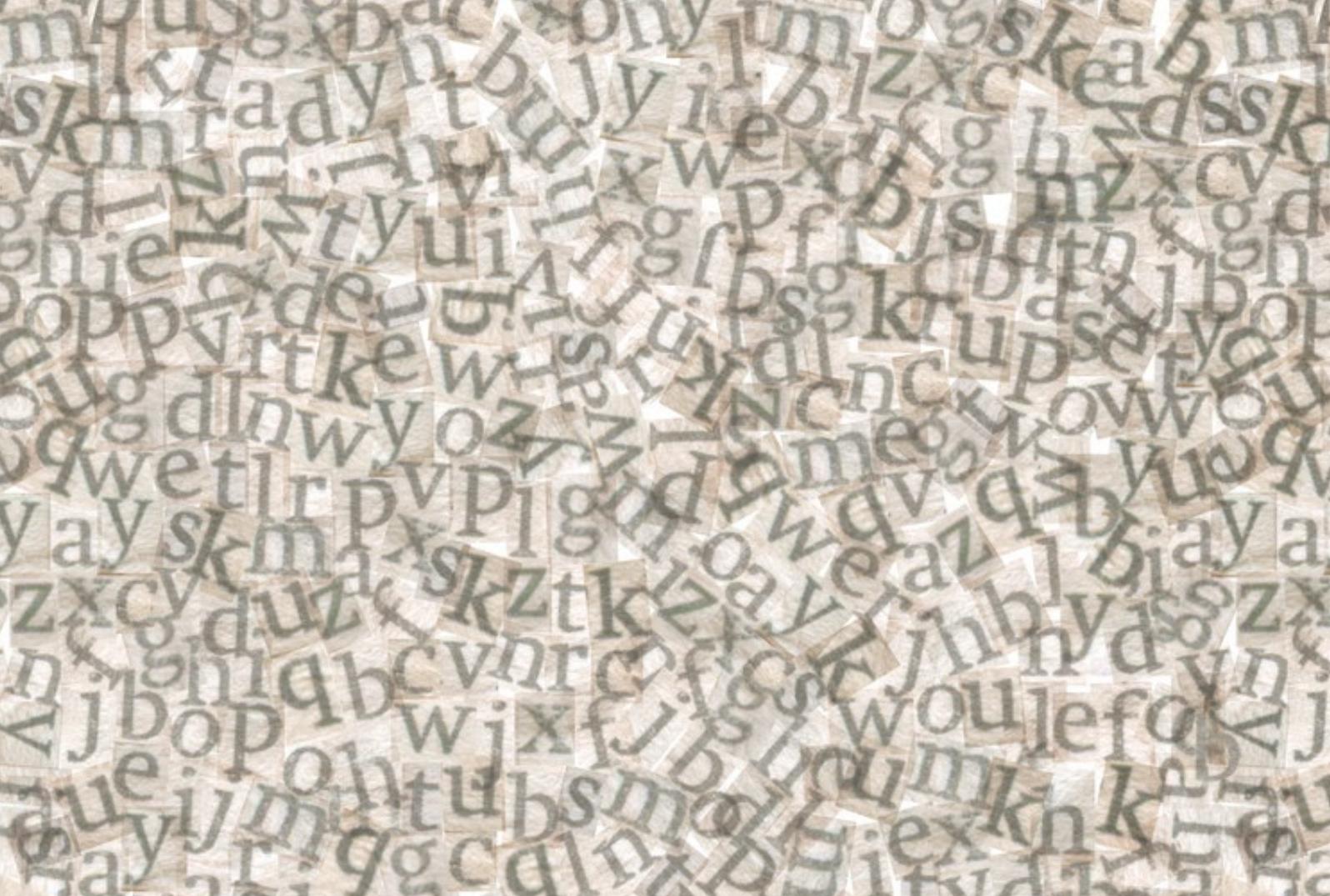
However, most participants considered the track and trace system to be the least effective measure implemented by the government:

“I did not see how track and trace would work anyway if I’m honest because the amount of people. Unless everyone’s doing it it’s not gonna work so I can see what they’re trying to do and I’m glad that they are trying to do that but don’t see how it can work unless everybody has it” (age range unknown)

“I think track and trace was least effective, that didn’t do anything because it wasn’t set up in time it was too late by the time they thought about track and tracing people and they don’t have the manpower to enforce it, so I think that’s a waste of time” (age range 25-40)

“I would say the least effective has been the track and trace system as it was never thorough and would have needed cooperation from everyone for it to be effective” (age range 18-24)

“I mean we’ve had people at work telling us that they were phoned like a week and a half after telling them that you’ve been in contact with somebody, you need to isolate, but by then it’s been a week and a half so that’s not been not very effective at all” (age range 55-64)



You muss
learn **to pick**
sense outta
nonsense

(Caribbean saying)

Invasion of privacy.

Some participants expressed concerns about an invasion of privacy and mistrust of the government and how data would be used in relation to track and trace:

“There’s a lot going on that doesn’t really need to, it’s invasion of privacy”
(age range 25-40)

“Why would you download something that would then penalize you and charge you £10,000 for stepping out of the wrong zone, you know, to me we’re not in Nazi Germany. So for people to agree to, you know, put these restrictions on themselves is madness. You know, we should all have the ability to use our own common sense and our own judgment as to whether or not we’re being safe and you shouldn’t be dictated to, this is not a dictatorship so there’s no reason for people to fall into this very strict regime”
(age range 41-54)

“I’m not totally sure about track and trace in that I think sometimes that spread a lot of fear, I’m not saying intentionally but because it put, as it were, an electronic tag on people” (age range 55-64)

We’re so close to martial law.

Younger participants expressed concern about being controlled and individual liberty:

“I think the government it has fast forward its control of what the government has over the average person. I mean we’re so close to martial law if a government can tell a whole whole country to stay inside the house for a year and if they actually do that you know government understand that they’ve got complete control over us”
(age range 18-24)

“I think a lot is just distrust in the government and just not wanting the government to have such a control over knowing everywhere we are” (age range 18-24)

“They didn’t want the government to stalk our every movement, people don’t trust the government anyway especially people who are my age so I don’t really see why they would give the government access to where they go more than we already do, it’s already tracked obviously but like with our phones and stuff, but I think actually having an APP was probably just a step too far” (age range 18-24)

“There was already a lack of trust with the government and this whole COVID-19 scenario and system that when you come to the point where you’re saying okay you’re going to have this APP... it was never going to work was it, not in England right, so for me the government was out of touch with the communities of England because they didn’t understand that that wouldn’t work right now. If they utilize their community services better, they would have gotten that information but everything was done centrally” (age range 55-64)

Impact

We wanted to explore the impact that COVID-19 and lockdown was having on participants.

I had to become a teacher at home.

Some participants spoke of the additional role they had to take on in home schooling their children and the challenges this brought:

“In terms of adjustment yeah like I said I had to become a teacher at home, getting him motivated, getting myself motivated” (age range 25-40)

“In the first lockdown I had to home school which wasn't going very great” (age range 41-54)

“I have to home school my 12-year-old son. During the first Lockdown I found this challenging but it's got better” (age range 41-54)

Several participants spoke of the challenges of home schooling their children whilst also having to work and trying to effectively balance these roles and responsibilities. Concerns were expressed about children falling behind:

“Home schooling whilst working to me is near impossible. The days I work from home my daughter hardly does any work due to my workload being heavy, not able to do both, so she may have fallen behind. My other kids can't wait to get out the house back to school and college. They miss socializing and their evening activities. I have personally found lockdown very hard” (age unknown)

“Home schooling has been difficult in which I will need to support my child when I come from work to go online to do his homework. This is particularly hard due to his special needs” (age range 41-54)

“My concern is for my children academically and they're not underprivileged but it's to me the time and making sure that they do what they're supposed to do” (age range 25-40)

“It's just not the same as it would be if they were in school” (age range 18-24)

He should have been in school.

Although most of the focus has been on health matters when thinking about the lockdown a byproduct of closing schools and churches has been the impact on young people and community relations with enforcement bodies. One respondent saw the impact of the lockdown in a wider sense after recalling the killing of 15-year-old schoolboy Keon Lincoln who died at 3.30pm after being shot and stabbed on 20th January 2020.

“... I mean if we look at all these kids are off school, a lot of them are turning to the road (streets). In Handsworth there have been about three stabbings the last few weeks and some of these are kids dying. He should have been in school” (age range 18-24)

It has definitely shone a light on the class system.

Participants spoke about the disadvantages of children from low-income families:

“I think with the education, I think it has definitely shone a light on the class system we have in Britain because I don't think any child regardless if you're poor or middle class, I don't feel that education should be different or the education you receive should be different just because you come from lower income families, and I think that's really sad to see. And a lot of that impacts Black people in terms of you know, lower incomes because of the areas that we live in” (age range 25-40)

“Kids that I work with a lot of them are from low income families and disadvantaged backgrounds but for multiple different reasons and some of them say that their parents can't work with them or help them with their work because they're working or some of their parents actually don't know what they're learning, like they don't understand... the parents are struggling to help them learn because their parents maybe are embarrassed because they don't know... they're not teachers” (age range 25-40)

Similarly, participants spoke about children being disadvantaged due to not having access to the equipment they need:

“The majority of the children who are in low-income families who would fall behind aren't white... asking children to learn from home and needing Wi-Fi access and iPad and laptops and all of these things that the school normally provides, I think that would be very difficult for a lot of parents, especially if they were struggling already. There should have been a lot more support from the government there” (age range 18-24)

“There was a move to equip the children with the relevant computers to maintain their education, however, it doesn't seem as though enough is being done, I don't feel that enough is being done, you know and I think that the advantage is in favour of people who do have the laptops and the skype and this kind of technology which is unfair really, it's highly unfair” (age range 18-24)

“If the areas that they live in is deprived and the school is deprived, the school doesn't always have the equipment and things to give the children in the first place, so they're already disadvantaged and now they're not physically in school... they can do stuff online but they need more one to one support and so, yes, I think they will fall further behind than they already are” (age range 55-64)

“My biggest concern is the children not going to school, it just creates a divide. I think, when you think of a lot of places and Sandwell is one of the poorest neighbourhoods in the UK, you can't go to school and his house might not have Wi-Fi, he's gonna have a different education and even though the school that he's gone into may have been the best school, he's gonna now not have the resources to even learn the same” (age range 18-24)

The intersection of health, poverty, all these things.

Concerns regarding health and poverty were extended to the Black population more broadly, with a number of participants stating that the pandemic had highlighted poverty and deprivation:

“What was the elephant in the room and denied until it was just not deniable was the impact on ethnic minorities, Black individuals. The intersection of health, poverty, all these things, which showed what we’ve already known. They have an impact on your health and therefore they have an impact on how you are able to respond to a pandemic” (age range 55-64)

“I think with Black people being at higher risk, I don’t think that’s anything to do with genetics, I think that’s more to do with poverty. You know, the NHS is full of like BAME people isn’t it. I don’t think there’s no scientific evidence from what I’ve read that melanin in your skin makes him more prone to covid, it’s just, you know, living where there’s poor areas, and you know bigger families, living in flats and, you know, where they are socially close, you know, they haven’t got like the space... there’s a lot of people, Black people living in social housing” (age range 55-64)

“Being on a low income wage is also what comes with it but it’s such important roles, whether it be a bus driver, whether it be a nurse, you know... it’s everything that’s keeping the economy running... there are key worker roles and they’re having to care for others and then go back to their families they’re constantly around you know others. Considering the message is stay at home, stay alive, they haven’t been able to, they’ve had to carry on going therefore putting themselves at risk, therefore, being even more at risk of dying so it’s almost like our lives have been put at risk at the expense of everyone else to keep everyone else alive it’s heart breaking” (age range 25-40)

“It does make you think about the underlying health conditions, we are known in our community to have certain hereditary conditions that may contribute to an underlying health condition which probably could make us more at risk, you know, but these are all factors and it’s almost like we’re not being safeguarded... Knowing that we are one of the communities and one of the ethnic groups that are more at risk, how are we actually being safeguarded... we should be safeguarded, a high level priority and I just don’t think we are which causes me frustration (age range 25-40)

People’s health conditions may deteriorate.

Participants expressed concerns about access to routine appointments and the long-term impact on health if treatment continue to be delayed:

“All of the emphasis appears to be on coronavirus understandably because it’s a global pandemic, but you do think and feel for people who have got other conditions which need to be treated, but that’s kind of been put on the backburner now with all the emphasis being put on covid so it’s really, really difficult and as a result of that people’s health conditions may deteriorate can get worse because the emphasis is on treating and looking into covid” (age range 18-24)

“It’s a worrying time especially if they’ve got Issues like dementia, even with cancer its a double worry or triple worry” (age range 55-64)

“There are people that I know waiting for operations and we’re talking cancer operations and other major operations all been cancelled because of COVID-19, that is wrong. That should not have happened” (age range 65-79)

The burnout was real.

Participants spoke about the difficulties they experienced working from home, managing tasks, and achieving a work life balance:

“There is an assumption that it might be easier to work from home. For me, the burnout was real. You need to have the ability to separate between work, church work, school and home” (age range 41-54)

“My work home life balance kind of merged so I need to make sure that I’m getting a break in because there’s so much screen time and so it probably affected me in that way, you know, people always think you’re readily available because you’re at home so you’re constantly becoming or seeming to be more efficient, fitting more zooms in but not necessarily looking after your own self making sure you’re having breaks and eating on time so that has been one thing” (age range 25-40)

“It can impinge on your work life and sometimes I’m sitting in front of the TV doing a bit of work as well” (age range 55-64)

I think it’s affecting everyone’s mental health.

Many participants spoke about the impact the pandemic and lockdown has had on their mental health and wellbeing:

“I think it’s affecting everyone’s mental health, regardless of race but I think it’s probably going to affect the ethnic minorities more just because we have a lot more, we probably don’t recognize it and I think this is the first year that we probably recognized it out in the open, is that we have a lot of biases to contend with in everyday life. We’ve got health biases, biases in education system, biases with the people meant to protect us like the police and we kind of battle that every day through little things and then now we’ve got covid and the bias of covid and the fact that it’s affecting us more and more of us are dying. So I think it’s going to have a much broader impact on our mental health and then the services to help Black people with mental health and Asian people are not there, and it’s difficult for us to get the help that we need” (age range 25-40)

“I suffered a couple of bouts of depression. I had my hair falling out and it was very difficult to get access to a doctor since March, until now I have not been able to get to a doctor” (age range 41-54)

“It affected my life, good lot of sorrow from family members passing, friends, close friends and you just sometimes don’t feel like getting up because you ask yourself what’s the purpose of getting up when there’s just nothing so you get fed up of it” (age range 41-54)

“I got extremely down and depressed. I had to ring my doctors get prescribed drugs and I was also dealing with racist neighbours on either side of me” (age range 41-54)

Some participants connected their deterioration in mental health and wellbeing to the lack of activity and isolation from their families and friends:

“I can’t get out and about. This causes a little bit of depression knowing that the places I would usually attend to release stress are shut down” (age range 41-54)

“I haven’t been able to work properly since last March, this has affected my mental wellbeing as I like my routine and going to work is a huge part of that, it’s like it gives you a purpose. Alongside that, not being able to socialize doesn’t help – I miss people, more importantly I miss seeing and being around my family” (age range 25-40)

“I have felt lonely and isolated due to not being able to socialize with family/friends also having traumatic life events during the pandemic does not help feeling of loneliness/isolation” (age range 55-64)

“It really affected me mentally and physically really because I like to go and meet my friends and keep active by going about but I wasn’t able to do that, so that really did affect me mentally really” (age range 80+)

Several participants spoke about the duration of the lockdown contributing to mental health difficulties:

“I understand that we’re trying to protect the NHS, I understand that but at the same time what about all the things that will come out of this lockdown, mental health issues that kind of thing I just feel like you’re trying to protect one thing but in another way there’s so much other things that are being affected... At first, I thought a couple months would be okay, we can survive a couple months in lock down, but an on and off lockdown for a year has been I think been doing more harm than good, to be honest” (age range 25-40)

“I’m really struggling with this lock down now, this third one I’m really struggling because the second lock down for four weeks was fine, but this one, like I said I’ve been distressed in terms of being tearful and emotional and sometimes just feeling lost, and I feel like I’ve got no purpose and lost my motivation (age range 55-64)

“It’s just too much it’s just too much you know you got people have to have something positive to look forward to” (age range 55-64)

We are tired of being stigmatized when things go wrong.

A WhatsApp report of a McDonalds outlet in China refusing African students’ entry and blaming Africans for coronavirus were widely circulated on social media.

https://au.news.yahoo.com/mcdonalds-coronavirus-sign-Black-people-not-allowed-guangzhou-002810779.html?guccounter=1&guce_referrer=aHR0cHM6Ly93d3cuZ29vZ2xLmNvbS8&guce_referrer_sig=AQAAABESJ0v0t6n4Y07ksM0NMZ-4n3zPbW9F_dROwHNobqw-aesl-4kK3ImJ6R94Ei-XsX1z8zYXU7sOGQhDfiMgSax3GHL1oMosF51yqZ3ssd3rrsmtl12scqzLQp-RdMvfrGSbRK24WxWP2z8wtpbGDno4vJkc5l_U7BOXhL97TyPZ

Several participants spoke about their beliefs that the Black population were being blamed and stigmatised during the pandemic:

“If they’re going to identify us being Black and ethnic minority groups, why do they have to place us in the category of being deprived, we are deprived because we are not being helped sufficiently by people in authority, by people who have the means to assist us and we are tired of being in deprived communities, we are tired of being poor. We are tired of being stigmatized when things go wrong, we are tired of it, the Black community is tired of it you know, we’ve had enough of it, and you know when there is things like a pandemic an epidemic infectious things, Black communities, Black people are being blamed, we’re tired of it” (age range 18-24)

“We are always the first to be picked on, we’re always the first to be scapegoated” (age range 55-64)

“I still feel that a lot needs to be done in support of the Black and ethnic minority groups to prevent us from being stigmatized and identified as being the source of infection, as being the people who are the problem. We’re not the problem, the infection and the virus are the problem but our community is being targeted in a negative way and I resent that” (age range 18-24).

“They’re still trying to make out that we are the cause, with the spread where, you know, we’re a problem and actually that’s not the case at all. Covid doesn’t know if you’re Black or white. I know that genetically there may be some reasons, but if there are then they need to explain what they are” (age range 41-54)

“We understand like a lot of things like covid how you know we’re portrayed that we can get it more than everyone else, we’re more prone to it, but the way they say it sometimes is not the best, but then makes us feel like okay we’re the ones that are prone to it and I’ve heard people say oh you guys should be the ones that don’t go anywhere because you guys are the ones that are most prone to it and I’m like oh okay that’s a bit rude” (age range 25-40)

Why couldn’t they supply us with any form of PPE.

Some participants commented on the government highlighting the increased risks to people from Black Asian and Minority Ethnic backgrounds but feeling as though no additional support was put in place to address these risks, such as provision of PPE. Respondents who worked within the health and social care field relayed feelings of being pressured to work in situations that put them at risk.

“Being vulnerable and we’re not supposed to go out, why couldn’t they supply us with any form of PPE. Why didn’t they check us and say okay here are masks, here are gloves, here are sanitizers, that’s how you’re supposed to be looking after the people that are classed as vulnerable, check on them regularly but it wasn’t there and it’s still not there, this fourth lockdown, national lockdown I haven’t had any food parcels haven’t had any phone calls” (age range 55-64)

“If they are identifying people as being part of the Black and ethnic minorities and not supporting us with measures that are in place to help us to cope at home in these times of the lockdown then it just seems a little bit unfair that’s all” (age range 18-24)

“I think for a lot of reasons sickle cell is a bit undermined especially in the UK is because it’s not something that affects the white community, so they don’t really count it as important. Yes, I did receive a letter to stay at home and even though I’ve commended the government, they really tried in supporting people, there are millions of people out there that needed support but for the identified people especially with sickle cell I think this support maybe wasn’t soon enough... I might have support from people, but what about those who do not have any support system” (age range 25-40)

“I think some people feel resentful because they pointed out that the Black and ethnic minorities were the ones mostly affected by covid and yet there were no additional measures to support Black and ethnic minorities in dealing with covid. There was one programme I watched it was on channel four or five and it was all about Black and ethnic minorities and covid. It was emphasizing in one sentence Black and ethnic minorities are mostly affected by the covid virus and they are in deprived communities so okay when they are making a statement that Black and ethnic minorities are mainly affected by the covid they have no special measures in place to assist us in coping with covid. I think the government has failed the Black and ethnic minority communities” (age range 18-24)

Some key workers who had a high level of contact with the public spoke about their experience of failures and poor practice, particularly in relation to provision of PPE:

“PPE, that was a big thing because I don’t think they were at all prepared with the PPE and providing PPE for the staff... I was on the ward actually when I came back off break and the correct mask wasn’t there for me to go back on the ward... I just point blank refused to go on the ward... I said we’re going to stand our ground, we’re not going back on the ward without the correct PPE but I know colleagues who feel pressured to do that but they can only answer for themselves. They fell down big time on PPE and the provision of PPE, I think that’s got a lot to do with the amount of deaths that happened... If you’ve got staff going on without the correct measures not only are they a risk to themselves but they are a risk to their colleagues and the patients as well” (age range 55-64)

World Events

Participants were asked to reflect on world events that took place during the lockdown and the impact of such events. The question had a prompt regarding George Floyd and the Windrush but without prompting the vast majority spoke of the killing of George Floyd and some to a much lesser extent spoke of the aftermath of the Windrush scandal,

This was a lot to process, especially during a global pandemic.

Participants spoke about the impact of George Floyd's killing and feeling as though this exposed a lot of racism, racial injustice and discrimination:

“The George Floyd incident was debilitating. I felt sick and uncomfortable to go outside for days after. I was angry and re-evaluating everything as the incident was terrible but hearing the responses afterwards from people was really eye-opening. I attended the Black Lives Matter peaceful protest in Birmingham as I felt as though I wanted to do something – this experience was overwhelming, we shouldn't have to be still fighting for basic human rights. This was a lot to process, especially during a global pandemic” (age range 25-40)

“The murder of George Floyd affected a lot of people of different ethnicities and just the brutal nature in which George was killed was very, very distressing and graphic and certainly made me rethink a lot of things about society” (age range 18-24)

“It feels personal and because of that it just breeds a lot more disgust, just feeling the injustice, discrimination, it just brings up a lot of feelings and it brings out the activist side of me and many others... It exposed a lot of truth and there is such a massive need for change... and the fact that this, as I said, the pandemic is affecting us more at risk is just it's all of a sudden it's almost like a personal attack it really is” (age range 25-40)

“The murder of George Floyd made me angry/ disappointed that injustices like these are still happening in the world today. I would say that it highlighted a lot of racism and biases within people- especially systematic racism” (age range 18-24)

“The Black Lives Matter movement, the George Floyd thing moved me because it's just like I think 2020 has been a year that's really revealed a lot of things that's not right with this world... we never know what will happen when we leave our house, it could be covid but it could be 100 other things if you know what I mean and I think the difference between covid and Black Lives Matter is that his life was taken away purposefully. I feel like with covid it's a virus that we may get you may not get, it may kill us it may not kill us but with Black Lives Matter with the George Floyd incident he had no care whatsoever the police officer that did it and I feel like that shows us more in terms of how people value life” (age range 25-40)

It hurts.

Many participants described their strong emotional reactions to the killing of George Floyd:

“We all have dads, granddad’s, uncle’s sons, cousins. It can be any of them it could have been any of them. It hurts” (age range 25-40)

“The murder of George Floyd affected me as a mother of a Black son, made me worry about our children’s future” (age unknown)

“That could be my brother or a family member. To be honest with you I was in tears” (age range 55-64)

“I was just in constant tears with that one and just thought here we go again there’s never any justice for us” (age range 55-64)

It’s still going on.

Participants described the longstanding inequalities they and others have experienced. Many felt the George Floyd killing highlighted this:

“Just to know what our ancestors have gone through from so long up till now it’s still going on” (age range 25-40)

“George Floyd most definitely affected me. This brought back my childhood memories at school when being picked on and being called the ‘N’ word. I honestly don’t believe racism will never change for the Black community. It makes me think about slavery, the Windrush Generation, especially the stories my dad had told me when he came to this country in the 50’s aged 10 years. This has had an impact on me physically, mentally and emotionally” (age range 41-54)

“What was going on in America, it wasn’t really surprising because you know growing up in the 50s, 60s... it’s been going on for years I’ve seen it and listened to it over the years, so it didn’t surprise me with this one” (age range 80+)

“I think it’s difficult being Black because the voice that you would normally have is not the voice that you present because you always feel that, well me personally, I always feel that somehow somehow if I say too much I’m going to pay for it negatively” (age unknown)

I feel like they don’t value Black lives.

Several participants felt that Black lives were not valued and gave examples of the role their parents and grandparents played in rebuilding Britain after the war which is often forgotten:

“I felt like [the Windrush scandal] kind of ties in with the Black Lives Matter thing as well because I feel like they don’t value Black lives and how we actually came over here to restore England after the World War” (age range 25-40)

“It had an impact on my family more than anyone else in terms of just like my nan... She came around the Windrush era, she’s a nurse so, you know, as were many other people especially that were Caribbean and yeah so hearing what happens to a lot of people is horrendous and then to issue an apology, are you for real like it’s shocking it was awful to know that so many people, the effect on so many people and considering how much value and skills they brought to Britain. It’s unforgivable” (age range 25-40)

Brexit sort of peeled it back a bit.

There was some reference to Brexit and how this might have contributed to more covert racism or discrimination:

“Brexit sort of peeled it back a bit, but when you get people writing and complaining about an advert about a Black family and about a father making gravy, you wonder when you’re sitting somewhere and you see all these people you’re like which one of you thinks that, and I suppose I hadn’t felt that way since I was young really” (age range 55-64)

“Racism is very much alive today, Brexit caused that. It gave people a voice that they didn’t have before... I think people now feel that they’ve got to be on a side and being on sides is only making humanity more divisive and that’s what I find quite scary is the fact that now people are picking sides... I think we’re always going to come across this and we’re never going to be accepted” (age range 41-54)

I’m happy that the world is changing.

Some participants were hopeful for change:

“I’m happy that the world is changing, the views of the world is changing regarding these things, unfortunately, it’s not something I think we can totally overcome unfortunately... I’m just optimistic that things are going to be better than the way it is now and things are getting better” (age range 41-55)

“BLM will hopefully lead to well overdue change, worldwide” (age unknown)

“People now are actually starting to voice their opinions whereas before they wouldn’t have. It’s made a lot of Black people within the NHS a lot more braver to speak up... I think it’s almost empowered a lot of the Black NHS workers to actually stand up and speak up for themselves” (age range 55-64)

“It just reminds us of the world that we live in... and just exposed things which you know gives rise to a lot of awareness and yeah hopefully new policy change” (age range 25-40)

Death and Bereavement

We wanted to explore the impact of death and bereavement on participants given the likelihood that participants would have experienced loss during the COVID-19 pandemic.

It's very disturbing, it was very traumatizing.

Many participants spoke about loss related to COVID-19 or other health conditions during the pandemic or lockdown. Several participants spoke about the impact of not being able to see loved ones in hospital and in their final moments:

“Because it was the very beginning it was like no sorry can't visit, no sorry you can't have a funeral or a normal funeral ... it will just never be acceptable to accept the way she had to go in this time, the way she went, the way it all panned out so that's affected me big time, I think it will do for a very long time... it's very disturbing, it was very traumatizing” (age range 25-40)

“People are still mourning the passing of loved ones suddenly taken from them, one day they're coughing or not feeling too well and then they can't even say their goodbyes when they're in the hospitals” (age range 65-79)

“Some people weren't able to see their loved ones at all, their last memory was seeing them go into hospital and then the funeral, that was not for everybody but that was for a lot of people and I think that's going to stay with a lot of people for a long time and be emotionally damaging for them... A lot of people are going to need ongoing support for a long time with their bereavement and deal with that emotion” (age range 55-64)

He gave up, literally.

Another issue that has arisen during the COVID-19 pandemic is the excess deaths in care homes. Older people in nursing homes returned some of the highest death rates as a result of the policy of discharging confirmed covid cases back to nursing and care homes. One respondent firmly expressed the view that the practice of locking residents in their rooms was a key contributor to the premature death of a grandparent:

“He gave up, literally. If he hadn't been locked up in his room 24/7 with no one to see I think he would still be with us, I think he died as a result” (age range 25-40)

Families have not even been able to grieve properly.

Participants spoke about the way in which the pandemic, restrictions and guidelines has impacted on the grieving process:

“Families have not even been able to grieve properly... We know within African Caribbean families we are known to have our setup and our nine nights, that's part of our culture... We have to just leave the grave and let the grave diggers put this stuff in, and you can only have 15 people at a funeral and so on, that's taken away a lot for some people” (age range 65-79)

“Imagine people in the family having to select who will be at the graveside... that is, you know, when people don’t get to grieve in the way that they would normally do” (age range 55-64)

“I have had a recent death in my immediate family, not being able to travel to the Caribbean to say our farewells is heart breaking” (age range 41-54)

“It was not being able to be around family and friends to grieve, that made me feel really isolated, lonely, it is quite challenging” (age range 25-40)

You can’t do the things you normally would do.

Participants spoke about the impact of not being able to support friends and family in the way they usually would, and not being able to engage in traditional practices such as visiting the person’s family and attending nine nights, funerals and wakes:

“I live in West Brom and we are like a little community as I said because we support each other especially in death, you know, we go to each other, we take stuff, we look out for each other and that just felt like a loss, it felt like you couldn’t support the people as you’d love to do it... All of us would be there together and remember, bringing back memories talking about the person, trying to support the person. We’d cook, eat, laugh, we drink, we play music, all that went through the door and that was a loss for me. It’s like we’ve lost all the things that made us who we are ... we cannot support them like we would so that makes you feel a little bit helpless and disconnected from it because you can’t do the things you normally would do” (age range 55-64)

“It was very strange not having to go to the house, you know, as a family unit to show support definitely the fact that it was done online is so surreal... It was just operational is the word, it takes the emotion out, it makes it very clinical and you lose the family interaction that is also needed for overcoming” (age range 25-40)

“It has been hard because we as a Black community normally have our big funerals, nine nights, wakes, and you all go there, you show your support before the funeral, you bring food and stuff like that so I know that it’s affected people” (age range 25-40)

“Some of these people their families are huge, not even being able to go to the funeral. People have died and we’ve not been able to do the usual things because that’s our way of supporting people you know you turn up with something on nine night everybody is sitting, you reminisce, you give people a hug” (age range 55-64)

Participants spoke of the difficult feelings they experienced as a result of not being able to offer the support they would have liked:

“They were videoing it all live so the rest of us could see, which I mean, you know, it was a little bit disturbing because we wanted to actually be there, you wanted to actually support the person there and you know one or two of the times you’re seeing these people break down and under normal circumstances we would have been there to comfort each other and they wasn’t able to do that so I just found that a bit difficult” (age range 41-54)

“We couldn’t give them the same support that they gave us when my grandparents died so it was a real shame” (age range 25-40)

“I suppose it makes me feel sad... the fact that you know people that you love dearly have passed and you cannot show your respect in a normal West Indian way as we like to do, we like to gather with other people and share memories of that person in their lives and so forth, you know, share our grief, you know, how we’re feeling about the passing of that person and stuff that we cannot do that” (age range 55-64)

She didn’t get the send-off that she deserved.

Some participants spoke of people not getting the send-off they deserved due to the restrictions and guidelines:

“She was very well known in the Black community and it was a shame because her funeral would probably have had hundreds of people there and so she didn’t get the send-off that she deserved” (age range 25-40)

“Black people on the whole when we have funerals they are very big gatherings and a lot of the people in the community we know one another and to know somebody you’ve known for how many years, and you would like to support their family, you’d like to wish them well, you would have liked to have been present at a church ceremony or the funeral and then to be told only 10 people can go at one point, and then I think it reached to about 30 people could go so I don’t think people was getting the send-off that they deserve” (age range 41-54)

“Not everybody’s able to kind of like celebrate that person’s life in a way they would normally do so again that can be quite difficult” (age range 55-64)

“It’s been very difficult for people who’ve had to make choices about who comes to a funeral” (age range 55-64)

There’s just going to be a lot of more depressed people.

Participants spoke about the long-term impact of losing loved ones so tragically and not being able to grieve in the usual way or follow important traditions:

“There’s just going to be a lot of more depressed people when covid is at a controlled stage, there’s going to be a lot of people depressed and they’re not even going to understand why, but you know these are the reasons because I don’t think that people grieve properly and you know life has to go on and they keep on doing everyday life until they get over stuff, and as soon as covid is at a stage where it can be managed people is just going to be in a lot of emotional problems” (age range 41-54)

“We’re not going to see the effect and I’m not going to fully know how I feel about it until probably a year’s time when it catches up with me that I’ve lost all these people and I wasn’t able to do anything about it or to show my respect in the way that they would want and I would want” (age range 41-54)

“It is not just people who have died of covid and that I’ve been close to, it’s also people that have died of cancer and I cannot grieve and it seems to be more hurtful and more lasting time to grieve because you’re not able to grieve properly at the normal or the right time of that person’s passing” (age range 55-64)

Attitude to vaccines, vaccine hesitancy and the likelihood of taking it.

Let’s take the vaccine.

Some participants spoke positively about the development of the COVID-19 vaccine as they felt it would help to protect people, reduce the number of deaths and help the country return to some form of normality:

“Let’s believe science, let’s take the vaccine as it has been approved by, you know, by the authorities as it is meant to save lives because that was the purpose of this development... we have to be protected and the only way we can protect ourselves is the vaccine” (age range 41-54)

“I think it’s a very good idea, I do think it will protect us and get this virus under control so that’s why I’m one hundred percent for it because I’m going to have mine... I think we have to follow this guideline that’s given by the government, because I’m sure it will protect us and everything to get back to normal quicker if we all follow the advice” (age range 80+)

“My thoughts about vaccines is quite positive... that’s just one element that could help us beat this covid, the more people get it the better... prevent people if they do catch covid from probably getting serious symptoms or being hospitalized or worse still death so I think it’s a good thing” (age range 55-64)

“I think it’s great that we’re having numerous vaccines and the emphasis is on the older people and those who are considered to be vulnerable and the rollout is going well, millions of people here have received the vaccination already and we just hope that it will help us to get to some kind of normality at some point” (age range 18-24)

A small number of participants had already had their COVID-19 vaccine and there were others who said they would accept the vaccine once it is offered to them:

“The reason why I think I took the vaccine was because I wanted to show my family and at least 50% of them are saying that you’re going to die or they’re going to inject you with a microchip, that they’re going to inject you with the mark of the beast I wanted to show them okay right I’m taking the vaccine now monitor me. I can give you an account of how I’m feeling so that rather than you just have one source of information or one approach to this you’ve now got two” (age range 55-64)

“When it comes to my turn to have the vaccine I will, I will have the vaccine... I am for it if there’s something that can protect you. Yes, I know some people remain sceptical and fearful but it’s a matter of choice... Some will want to have it, some will not... prevention is better than cure” (age range 65-79)

“I don’t like them, but I will be having mine” (age range 55-64)

I am not taking it.

A number of participants were very clear that they would not take the vaccine:

“I am not taking it there’s no way on earth I am taking it, I’ve had this debate with so many different people and for me personally I don’t take vaccines anyway” (age range 25-40)

“I don’t intend to have the vaccine, very unlikely, I’ll take my chances” (age range 55-64)

“Can I say a Hell No” (age 25-40)

“I said I’m not having it because I’m not sure about it and I’m not going to be a guinea pig” (age range 80+)

We are being used as guinea pigs.

There were many participants who did not want the vaccine due to concerns about the vaccine being new and not knowing if there will be any long-term side effects. Many spoke of feeling as though people, particularly Black people, were being treated as guinea pigs:

“A lot of Black people are very sceptical about not only the vaccine but the virus and certainly there is a big concern that we are being used as guinea pigs for this vaccine and if you go by history there’s validity to that view and to the argument that Black people have traditionally been used as guinea pigs for a lot of medical experiments and that fear of being used again is a very real one. It’s going to be difficult for policymakers to overcome that fear, so I would say that it’s unlikely that a lot of Black people will be signing up to take the vaccine” (age range 18-24)

“A lot of the Black community feel that the covid vaccine is dangerous because it’s not fully tested, that we as the Black community are being used as guinea pigs for the covid vaccine” (age range 18-24)

“We have not really had much trust in the NHS as it is, Black people for generations being used as guinea pigs” (age range 41-54)

“The fact that it has been affecting our community more than ever it’s a nice way of saying you guys need it first to safeguard yourself but then what are the implications of taking that, what does that mean for health 20 years down the line for us. Does anyone really know what it could do to our children, for our children’s children. there isn’t enough information at the moment out there that we can really understand not in a condescending way but in a way that would be palatable for the average non-academic to actually understand” (age range 25-40)

We don't know what the long-term effects are.

“My main concern is the fact we don't know what the aftermath will be of the vaccine because it's not been tested for long enough and that's why I don't want it in my body at this point. I understand that we need to vaccinate against things and that's really why they're pushing it towards Black people, the elderly, you know, like I have already discussed, the Black people aren't seen as valuable. Anyway, the elderly is a massive drain on society financially so again those are two groups that aren't seen as valuable. So those are the people that will get in my opinion will get vaccinated”
(age range 41-54)

How it's going to affect fertility.

There were particular concerns around the vaccine affecting fertility. These concerns were primarily expressed within the younger age groups:

“I've got no idea what it's going to do to me, like well the things that are important to me, how it's going to affect fertility and you just think they've even said they don't know so I don't really want to take that and I'm not at risk at the moment, I think I could probably fight covid if I got it and so I don't really see the point in risking other things when I can probably beat covid” (age range 18-24)

“I'm not going to have the vaccine I'll hold off as long as I can hold off having the vaccine because I feel like it's too new and I don't think it's been tested enough and especially with the side effects and obviously I still want to have children... there may be adverse effects because I feel like I'm not sure how they managed to get a vaccine so quickly... I'm not willing to take it right now, and I want to see how it pans out first” (age range 25-40)

“I do not agree with the vaccine as I believe that research has been rushed and we are unaware if it will cause future defects e.g.in fertility, being prone to certain health conditions etc. Also if the vaccine is safe/ effective for BME individuals” (age range 18-24)

“I think most people are sceptical about the vaccine as it has been produced really quickly, they aren't recommending it for pregnant people as they don't understand the full side effects – this just doesn't sit well with me. I'm sure they are still working on ways to improve the vaccine yet they are injecting people” (age range 25-40)

“I don't know where it's come from, I don't know how quickly that was developed, what the side effects are I just have visions of the thalidomide children, I don't know if you remember that, pregnant women were given this vaccine, whatever it was for, and then you know, nine months later that's when they saw the effect of the vaccine so honestly I haven't made my mind up at all about the vaccine my mind is still open” (age range 55-64)

There's a history of Black people being experimented on.



Participants in the infamous Tuskegee experiment

Many participants spoke of a history of racial inequality, racial injustice and structural racism influencing current mistrust of the government and medical professionals. Several participants referenced previous experiments that have been carried out on the Black population, such as the Tuskegee syphilis study. For these reasons, some participants did not think much of the Black population would accept the vaccine:

“Being a Black person, you know there’s a history, Black people being experimented on when it comes to you know, drugs... there’s Tuskegee... it is like a 40-year experiment where they were injecting Black people with syphilis and not telling them. You know, to see how they died out, there’s things like that you know which we all know about in the Black community just them basically experimenting on Black people, you know, with drugs in Africa and this is why the Black community would be sceptical.... saying Black people are like 72% vaccine hesitant as they’re putting it but it’s not through superstition or anything it’s through what’s gone on over the years, which wouldn’t have made mainstream media news” (age 55-64)

“Black people are never at the front at the queue for nothing so why now?” (age range 41-54)

“Because of how it has constantly treated Black people, whether it’s mental health or just any kind of health issue that we was at the bottom of the list or not believed, you can’t turn that around on its head and say, oh but in this case you’ve got to believe us we’ve got your health at heart, when you spent the last 30-40 years dismissing Black people in terms of mental health and their physical health” (age range 55-64)

“There’s a lot of problems with us not getting the right care a lot of the time and I don’t think that’s a coincidence, I think if we look at like the death rate for Black females giving birth it’s like five times higher than other ethnicities, I just don’t think that’s a coincidence” (age range 18-24)

“Why do people that hate Black people want to turn around and now try to say they want to save us I don’t believe that and I don’t accept it, to be perfectly blunt I don’t accept that, and you know they want us in the lowest paid jobs in the deprived areas and all those things and the inequalities in healthcare and suddenly it’s like no, you must take this vaccine and it’s going to save you, really well you’ve been trying to kill

me for hundreds of years and everybody that looks like me for generations and so why is this any different and why are we most susceptible because I've yet to hear answers about what makes us, because we're Black, more susceptible, is it our overall health is it our diet, what is it that's making us susceptible" (age range 55-64)

"What has the government done for us, and I think because of that people are wary, I can understand why, never been prioritised and never been focused on really in a way" (age range 25-40)

There's not enough transparency.

A number of participants said they had very little information about the vaccine and wanted more detailed information and more transparency:

"We need to see the people who are making these things show us that they're taking it themselves to reassure people... there's not enough transparency from government" (age range 55-64)

"Because there's doubt, call it ignorance as well, I'm not afraid to say that I don't know exactly what's in this vaccine and then exactly the implications, but then I mean what do I know about any jab, but at the same time there isn't enough to satisfy me to fill me with confidence to take the jab at this particular stage, and so because of that I at the moment I am not willing... I think everyone's got to make a decision based on themselves... for me personally I would need a lot more information to satisfy me to make me a willing guinea pig and so that's my thoughts on the vaccine" (age range 25-40)

"Where are they getting the figures from. It could be 72% of 10 Black people, so you know what's the actual figures you know... because then it sounds like 72% of the whole Black population so again, this is where you know I get sceptical about why they're trying to do that... we don't know about the sample size" (age range 55-64)

"What I'd like to do is actually sit down and talk to a person who's involved in this virus vaccine and who can give me the figures and let me know well, when you did your trials how many Black people were in there because usually when they do all these things they don't include us Black people, they don't come around the community or contact the churches and say right we'd like some Black people for this study... And so, how do we know this vaccine is going to work on Black people" (age range 55-64)

I think it should be compulsory for all.

When asked about making vaccines compulsory, a small minority of participants believed the vaccine should be compulsory:

"I think it should be compulsory for all" (age range 55-64)

"I think it should really become compulsory because it's no good some of us having it and others refusing... The virus will still be around if others don't have it, I think it should become compulsory" (age range 80+)

“Well, to me, if the person’s got no form of allergy they should have it, that should be compulsory” (age range 41-54)

I don’t think the vaccines should be compulsory.

The majority of participants did not think the vaccine should be compulsory, this was discussed in relation to freedom of choice and human rights:

“I don’t think the vaccines should be compulsory whatsoever, I think it should be optional for everyone if they don’t want to take it then that’s on them to protect themselves, and if they do want to take it then go ahead” (age range 18-24)

“I don’t feel the vaccine should become compulsory for anyone, I believe that people should have the right to freedom of choice” (age range 55-64)

“I don’t think anything should be compulsory, I think if we’ve got the understanding to make decisions, we’ve got the capacity... if you’re going in the direction to restrict people that have not taken the vaccine perhaps they are and is that going to breed more noncompliance, possibly uproar or is it against human rights, it’s questionable it’s debatable... you can’t force something like that on someone so I don’t think it should be compulsory at all I just think everyone should have a choice and it’s up to them whether they feel it’s something for them, it’s up to them” (age range 25-40)

“I don’t think it should become compulsory because the person should be able to decide their lifeline, whatever they want. It’s like if you if you’re dying or you’re ill and you don’t want to be resuscitated, no one should do it, you should be able to make that decision yourself. Nobody should run your life that much that you haven’t even got the right to say I don’t want this because somebody else says you must have it, no it shouldn’t happen that’s taking away your rights completely” (age range 80+)

“It shouldn’t be compulsory for anybody, you should have a say in whether to take something into your body” (age range 25-40)

There’ll be some sort of restriction.

Many participants believed that the vaccine would not necessarily become compulsory but that there will be conditions or restrictions in relation to travel, employment or attending events:

“I don’t think it will be compulsory for all but I think there’ll be some sort of restriction that makes it somewhat compulsory. For example, to fly to certain countries you’ll need a vaccine or to come back to the UK you’ll need a vaccine” (age range 18-24)

I think it will become compulsory in terms of traveling I don’t think we’ll be able to go away on holidays without having that, I can see that happening in the future. I don’t know if it should be because I mean it’s your body, you should be able to do what you want to do with your body but I also understand that right now I guess they feel that’s the only way to try and get back to any type of normality (age range 25-40)

“I don’t think it will be compulsory, that you will be forced however I do think that you will be backed into a corner in terms of if you want to go on holiday, attend gigs and festivals – the normal stuff that we haven’t been able to do then you will have to have the vaccine” (age range 25-40)

“I can see places where okay you can’t travel to a country unless you’ve had the vaccine, you know, and can’t go to a job unless you’ve had the vaccine. I think you know it will become compulsory like you know through like the back door” (age range 55-64)

“I know I’ve got work friends with who are fearful about losing their job if they don’t have the vaccine” (age range 55-64)

Since completing the interview aspect of the research, the government announced a consultation on workers in care homes having vaccines.

On 14th April 2021 the government announced an open consultation on making vaccination a condition of deployment in older people’s adult care homes

The consultation was on the back of the knowledge that of the employer related deaths, those working within the care home sector were the most affected. Under the government consultation they set out the reasoning behind the consultation.

Persons requiring vaccination:

“It is our intention that the requirement to be vaccinated applies to all staff deployed in a care home supporting at least one older adult over the age of 65. This will ensure that vaccination coverage protects individual workers and people living in care homes and protects against the risk of outbreaks in the care home. This in line with advice from the SAGE Social Care Working Group.

<https://www.gov.uk/government/consultations/making-vaccination-a-condition-of-deployment-in-older-adult-care-homes/making-vaccination-a-condition-of-deployment-in-older-adult-care-homes>

On 15th June 2021 it reported that they will be seeking to make it compulsory for care workers working in care homes to be vaccinated. The implications can be far reaching as the care home industry has a high level of staff from Black African Diaspora communities.

AMA Journal of Ethics: COVID-19 Vaccine Hesitancy in the Health Care Workforce

Compliance

We explored participant's views on compliance amongst the Black population.

They are more likely to comply.

There were mixed opinions in relation to compliance with rules and restrictions amongst the Black population. Some participants believed that the Black population were compliant with the rules and restrictions:

“They are more likely to comply, as long as it is peer driven and community focused. I seen a Black lady, she was the first to wear the mask and people called her overprotective” (age range 41-54)

“I think that the Black and ethnic minorities will comply with the restrictions because they don't want to feel within themselves that they haven't done enough to protect their own health, however, I think that they do feel resentful of the fact that as a group they've been identified as needing to be a community that is spawned as spreading the virus even more” (age range 18-24)

“I think we are more likely to comply with restrictions because we understand the severity of the virus” (age range 18-24)

“I don't think there's a lot of Black people who are openly flaunting the laws, yes you do have pockets of Black people doing that but by and large you don't find you know Black people in in mass out here, having parties and you know, things of that nature. I think Black people are respectful of the rules. I think a lot of people understand that we are more likely to contract and die of the virus and as a result we have to take extra precautions to keep ourselves safe” (age range 18-24)

Less likely to comply with restrictions.

There were other participants who did not believe Black people would be compliant with rules and restrictions, this was linked to suspicion and mistrust:

“Less likely because of what's going on in the world – they don't trust” (age range 55-64)

“Less likely as we are more suspicious around the true intentions of the restrictions imposed” (age range 18-24)

“Less likely because we are tired of being controlled and repressed” (age range 25-40)

“Initially, when this covid came out we heard that he said Black people don't get the covid so we didn't at the time, but now that we can also get the covid I think they will comply with what's going on yes” (age unknown)

Other participants spoke about noncompliance in relation to having big families and the home environment:

“I think they’re less likely because we all come from bigger families. We are communities that stick together. We are communities that tend to do things as a group because we feel safer to do so, especially in a country where we are a minority, so we will stick together. We have to, that’s the only time we feel safe” (age range 41-54)

“We have a higher prevalence of poverty and will be in lower income households which means people will have a lower quality of life, so asking people to self-isolate in households where they are living 24 hours a day, then you will see people more likely to break those restrictions however this will not happen in the upper class as those people have more money and they are more affluent white families, they’ve got more luxuries and liberties in their household so it would make sense that they’re more likely to stay in the house or they won’t break lockdown rules because you’ve got more, like more things to do at home and a better quality of life while you’re in the house” (age range 18-24)

It isn’t a one size fits all.

Some participants believed there might be age differences in relation to compliance and adhering to the rules and restrictions:

“It isn’t a one size fits all. It’s going to be down to who within the Black community would be complying, maybe older people would be more likely to comply, younger people less likely. I can’t say that blanket yes or no, it’s down to sort of different generations doing it for different reasons” (age range 55-64)

“The older generation complies with it but I’m not sure about the younger generation” (age range 55-64)

“I think they will follow the guidelines especially the older generation, they will follow the guidelines. I don’t know what the young people would do” (age range 55-64)

Life after lockdown.

Participants were asked about their views on life after lockdown.

It’s a new way of life.

Many participants described a ‘new normal’ after lockdown as they could not imagine things returning to the way they were before COVID-19 particularly in relation to working from home:

“We’re just really in here for the long haul, even my employer is looking at it from the point of the long haul. We’ll be working from home and it’s almost like really become the norm now. Really it’s a new way of life, and I think we’re going to be in here for a long time and it’s not just about the UK you got to think about other parts of the world as well” (age range 55-64)

“I think looking at the various types of work styles and home working I think that that could be an opportunity which they could kind of extend and keep in place for some people depending on their situations and circumstances which would help their home life balance” (age range 18-24)

“I think there’ll be less people going into physical buildings for work. The employers will be a lot more respectful of people saying I want to work from home two days a week... We will be a lot more nimble and flexible and I think you’ll have a lot more remote based jobs, a lot of people will work full time from home” (age range 18-24)

“I don’t think things will ever go back to normal but to be honest I don’t even like to look that far – these days what has worked for me is just taking each day as it comes” (age range 25-40)

Some participants expressed concerns about future life and socialising:

“I feel like it’s just going to be very different and I don’t think there’s going to be much human contact anymore, which I think is sad” (age range 25-40)

“I think people are gonna still be very suspicious of one another, I don’t think people will meet in large numbers like they used to” (age range 41-54)

Hoping that the vaccine will be effective.

Some participants hoped that the vaccine would be effective and contribute to the return of some normality:

“I’m hoping that lockdown will essentially calm down and go away. I’m hoping that the vaccine will be effective” (age range 18-24)

“I feel with the vaccine being rolled out we can slowly return to life pre COVID-19. Hopefully after lockdown has ended we can start to enjoy the social events we have missed for the past year” (age range 18-24)

Freedom and the ability to be able to be around my loved ones.

Some participants were looking forward to having more freedom after lockdown, particularly spending time with others and participating in activities they did before the pandemic:

“Freedom and the ability to be able to be around my loved ones whenever I choose instead of this being dictated to me” (age range 18-24)

“Hopefully, some resemblance of life prior to the pandemic. However, I do feel things will never be the same as before (age range 55-64)

“Businesses to open back and everybody to survive and bounce back after this” (age range 25-40)

“Hoping things will go back to way things were before covid, and going on holiday” (age range 41-54)

“To see my family on a regular basis as and when, and my friends and go out and enjoy meeting people” (age range 55-64)

More financially strapped.

Participants spoke of the financial implications, particularly for companies and individuals who have lost income over the course of the lockdown and the increased cost of living:

“I think people are going to be more financially strapped” (age range 41-54)

“I think there are going to be a lot of companies closing down and there will be higher rates of unemployment and that is going to last for like a few years” (age range 18-24)

“Very concerned about all business that have closed with regards to the effect on our economy” (age range 55-64)

“I personally think in terms of the rich poor divide, I think it might, you know, widen because I think there’ll be more people going after fewer jobs, so those who are poor are going to be more poor... with the Brexit situation you know foods going to go up because of import tariffs and all that kind of stuff so life’s going to get harder after this covid for a lot of people” (age range 55-64)

“Some of the low-income families may be affected as well by the work situation, being furloughed, all the companies that they work for laying them off and things so it’s not a great position because they’ve got more pressures that can lead to obviously mental health issues and depression and things like that” (age range 55-64)

It’s got to be better.

Some participants spoke of life changing for the better after lockdown. This was linked to being more appreciative, developing new insights and lessons learned since being in lockdown:

“It’s going to take time to recover, it’s going to take time to get back to normalcy, but normalcy has got to be better. It’s got to be better respect, better attitude, with a view of developing better, a better environment and atmosphere for us to have a better life, particularly for our elderly and our children” (age range 55-64)

“A lot of having fun and living life a bit more. I feel like people will not take their life for granted and will start to just live like every day is the last and have more fun, stop being negative. It will probably be a better world you never know” (age range 25-40)

“I kind of feel that we should be more loving and caring to each other and, in particular, our older people and that society should be embracing Black people more” (age range 55-64)

“I think people will value, including myself, human contact, your mental health. It will start to become more aligned... It is giving people a chance to think about themselves in the future, so I think people start to make more meaningful decision making around their careers around themselves, around their choices, around their lifestyle.... I see a lot of community unity at the same time, and definitely us all singing from this very similar hymn sheet” (age range 25-40)

“I view life differently now, you understand that we can die anytime, we should just be good to people at every time and live a positive life, and we should treat each day as if it is the last. I live each day as if it is the last.” (age range 25-40)

“I will also hope that people are going to be more, as a result of all of this, more compassionate, more friendly, more neighbourly than they ever were before and not thinking about all the material things material things etc... people will be hopefully more compassionate, more caring, more understanding and more looking out for others and showing more charitable generous generosity and kindness of spirit” (age range 65-79)

Considerations for the government and policy makers

Participants were asked what the government and policy makers should consider when looking at Black people and COVID-19 in the future.

Utilizing community influencers and community groups.

Participants spoke of the need for increased engagement with community organisations:

“They need to find ways of utilizing community influencers and community groups that are close to those individuals who look at things differently because of their experiences” (age range 55-64)

“Use key people from those communities that are trusted, whether they’re local or national people or find ways to communicate whether that’s local radio, national, tailored adverts, you know, something sent in the post from local voluntary organizations. Fund those local initiatives, fund people on the ground who’ve been communicating with Black people, communicating with us when all of a sudden we’re not in flavour and the government just drops us until there’s another issue, another Windrush, another riot” (age range 55-64)

“We need things like the African Caribbean centre, we need that for the youth, that for elderly, that for the middle aged” (age range 18-24)

“It’s just down to a community leader somebody that they can trust going into the community and explain. To actually go in from school age and they need to have somebody of knowledge of the community and educate from the big to the younger ones, the middle aged into the elders. They need somebody that the community

recognizes to go in and educate and give proper answers to questions that the community, you know, the minority group needs to get answered, you know, why is it that we as a group are more susceptible to it...They need people to go in the community with the community and bring back community centres where it used to be community centres where a group of people could go and have meetings like the council. They've got the council house, when they go in they have meetings to talk about the local communities or the city or the town, that's what we need, centres where, you know, the BAME community go to and be educated in all manners in a language that they understand. That's the problem we're not educated or told in a language that the BAME community understands" (age range 55-64)

Participants also spoke about the importance of government agencies and representatives increasing engagement with the community alongside working more closely with community organisations:

"They need to go into our communities. They need to appoint what I would call community champions, community ambassadors to help them, people who speak the language... People who we can relate to" (age range 65-79)

"Getting out into the community I think, engaging with the communities, like community centres, places of worship maybe getting right in you know" (age range 55-64)

"Go and engage with communities, it's about community engagement just like what you're doing at the African Caribbean Centre in West Bromwich, where you go out and you make sure you bring the communities together and you engage with them and you have events and so on, that's community engagement, community cohesion" (age range 65-79)

A representative that looks like us.

Many participants spoke about the importance of representation in helping to get key messages across to the Black community and to help inform appropriate decision making and policies for the community:

"I think what the government needs to do is properly provide information, facts and figures on how ethnic minorities are being more affected with the virus than anyone else. If they have that information they need to put it out there in places where Black people can see or maybe speak to them, organizations or social media platforms that they use or maybe get a representative that looks like us in from central government to you know get that message across them" (age range 25-40)

"The local authority could set up a group of BAME staff who can come up, probably just think about projects and things that can go directly to the community that's how they could use Black people who work for the local authority" (age range 55-64)

"My advice would be to ensure that whoever is delivering the message are people who are from African Caribbean communities and people who have some level of respect and traction with those communities and are able to demonstrate the value of the vaccine and how it can improve their lives and the lives of loved ones" (age range 18-24)

“I feel that if there was more representation of Black people stating the facts, giving their experiences of having COVID-19 / the vaccine perhaps we would take it more seriously” (age range 25-40)

“We need Black people more involved in the, in the NHS policymaking and decision making because there’s no Black people involved in their decisions at all, you might have 100 people making those decisions, only one of those are going to be Black. We need more involvement and more say” (age range 55-64)

“You can’t make a decision for a set of people without those set of people being involved and that’s what I find that government do, they speak to a lot of people in high places in our community but a lot of these people are not a true representative of the whole of the community “(age range 55-64)

They need to give us more information.

Participants said they wanted more information, particularly information that is clear, consistent, accurate and relevant. Participants also spoke of valuing statistical information and evidence:

“They need to give us more information, to provide figures and they need to be accurate, need to be true. They need to not be contradicting because you have one source will say this, and one source will say no that’s not right, the facts need to be the facts and the science needs to be tested properly if Black people are to be fully obedient and adhere to all of this that’s going on” (age range 25-40)

“Providing more information that will be useful about the impact of covid on us as a community, I want to say that more information and more stats... providing more guidance that I can identify with” (age range 55-64)

“They need to be clear about why, when they say we’re overrepresented, why are we overrepresented? How? Give us the numbers and then explain to us why we’re more susceptible.” (age range 55-64)

“We don’t have to have condescending messages delivered by people who don’t understand our community... we are human beings who can process information as well as anybody else, so I would encourage policymakers to treat us with the respect that you would treat any other community... Let people understand what the key messages are but don’t go overboard because we will certainly rebel if we feel as if we’re being spoken down to and condescended so just policy makers to keep that in mind” (age range 18-24)

Some spoke about the presentation of information and ensuring information is presented clearly and in straight forward terms, including use of different modalities such as short videos:

“I’ve seen on websites... cartoon type things, which in simple terms explain what the virus is, how it attacks the system, what the vaccinations do and don’t do but they all have American accents on them... you need to invest some money because a lot of money has been given to these various groups getting website designers or film directors or so on to, in simple plain language, do short videos or podcasts, which can then be put into the public domain for people to say, ah that’s what it’s about now I am better able to understand what this is saying and so on because at the moment the government’s messages is still not all together clear (age range 65-79)

They’re showing their press PowerPoint presentations and talking charts and spikes and all that and I mean they just need to keep it simple, keep it basic so people understand” (age range 55-64)

More measures in place to support this deprivation.

Participants believed it was important for the government and policy makers to consider the role of poverty and deprivation and address these issues within the Black population:

“I’m hoping that there will be more measures in place to support this deprivation, this poverty of Black and ethnic minority groups the other side of lockdown. I’m hoping to see more being done for children suffering poverty and educational problems arising out of lockdown. I’m hoping that their support will improve dramatically and I’m hoping that the Prime Minister will put more into the NHS to help people with underlying health problems” (age range 18-24)

“Black people in a lower social category in terms of finances, you know, are more susceptible so maybe it’s a case where families need to be supported more, you know, we’d like food vouchers or whatever, you know, educational support... you need investment into inner city areas” (age range 55-64)

“I just imagine that there’s laptop graveyards in organization’s offices where actually these things can be distributed out to families. They can get them wiped and send them out to families... and not only laptops, you know, whiteboards, desks, tables, lamps. There’s a lot of wastage out there, things that can be used right now that are sitting in organization’s stationary cupboards” (age range 55-64)

“I think a youth club needs to be installed so the funding needs to go to the youth and needs to go to the charitable centres” (age range 18-24)

“Keep the community together, you know, and enhance the community because that’s not being done at the moment. There’s nothing, I mean to me it’s been eroded from time anyway because we used to have community centres and all these kinds of things where you know we could go and play dominoes or whatever, all those things have been shut down” (age range 55-64)

Ensure Black people are getting the same level of care.

Participants wanted the government and policy makers to ensure that Black people were getting the same care as other races:

“Ensure Black people are getting the same level of care as other races” (age unknown)

“The key message to government and policy makers is to make sure that as Black people we are treated fairly” (age range 18-24)

“I’d like them to raise awareness as to the Black experience and how different it is from the white experience and then understand what comes with that and therefore shape their decision making and policies to be more inclusive, to be more considerate” (age range 25-40)

They need to develop a lot more of our trust.

Similarly, there were concerns around trust and suggestions related to building trust between the government, policy makers and the Black community:

“They need to develop a lot more of our trust anyway because, you know, with Black people and the way things have happened in terms of we’ve had the Windrush scandal, you know, there’s been lots of things that’s happened to our community that can cause a lot of mistrust” (age range 55-64)

“They need to make us trust them more, they need to stop pumping the rhetoric that Black people are the carriers, they need to stop making out that Black people are the cause of spread because that’s not correct and all that does is cause mistrust and hatred towards governmental bodies really” (age range 41-54)

Investing in more research for the health of Black communities.

Participants believed it was important for research to be conducted, specifically research that is focused on issues affecting Black communities:

“Investing in more research for the health of Black communities” (age unknown)

“Undertake research and with Black people in general to find out why it is affecting us disproportionately and finding steps in order to kind of minimize the risk for us” (age range 18-24)

“I feel there needs to be an NHS report into what’s going on with the BAME deaths and it’s not even just within coronavirus I think that’s within a lot of things” (age range 18-24)

BAME is a very, very, very generic term.

There were participants who did not find the term BAME useful. These participants highlighted the differences between ethnic minorities, cultural and religious practices and traditions that may not be considered when using the generic term:

“They need to kind of break it down more into ethnic groups and see what each ethnic group needs because each one would be different and I think they need to stop saying BAME are more higher risk or whatever... BAME is a very, very, very generic term and I just don't think it should be used anyway... how can you compare someone who's Black to some other ethnic minority, they're just totally different it's such a general term and if they stopped doing that and actually targeted the ethnic groups specifically then it would just be a lot clearer on what's going on because at the moment we're being kind of pulled together with people who are Chinese or Indian and it could affect them completely differently” (age range 18-24)

“They've got this new name for us now this BAME that I never heard of before lockdown” (age range 55-64)

“The groups and the cultures are totally different, the Black community is totally different from the Asian community in all aspects of religion, of culture, they cannot band two cultures together if the cultures don't marry, they don't mix, it doesn't work. I don't know how they can come up with the name BAME community when the cultures are totally different” (age range 55-64)

Discussion of Interview and Focus Group Findings

The findings revealed that irrespective of the initial response to the lockdown – feeling surprised or prepared – many participants had struggled with the lockdown for various reasons including reduced social and leisure activities, lack of physical contact with others, increased isolation, uncertainty, fear, and worries about the future. Some participants spoke about the impact on mental health and wellbeing which is important to consider, particularly given the societal challenges and racial inequalities that are known to impact on mental health, access to services, and outcomes for the Black population (Rethink, 2020).

In terms of accessing information about COVID-19, the majority of participants obtained information from mainstream news and official sources. Some participants relied on family, friends and third sector organisations for additional support and resources indicating the importance of these support systems. Most participants were aware of information being circulated via social media platforms and although this had contributed to some participant's views, the majority spoke of misinformation and conspiracy theories circulating online. Most participants did not rely on this when making decisions and there was little offered to feel this information influenced their views, decisions or actions. For those aged 55 and above, there was far less reference to social media as a source of information, so its influence was limited for these age groups.

The reliability of information was queried irrespective of the information source, this was often attributed to contradictions and ambiguity in the information being given. Despite this, most believed that official, credible and regulated sources were most helpful. Many participants felt confident in their ability to scrutinise information, do their own research

and use their own initiative in decision making. For some participants, they considered limiting the intake of information essential for their own mental health and wellbeing, due to the nature and volume of the information being reported especially on the back of four years constant Brexit news.

Information was frequently described as confusing, contradicting and changing too frequently. Some linked this to reduced compliance and adherence to the rules as people may be unable to keep up with the changes. A small proportion of participants expressed sympathy for the government due to the unprecedented nature of the pandemic and how this might contribute to the gathering and dissemination of information that is used to inform decisions.

All participants were aware of the measures put in place by the government and the vast majority believed the first national lockdown had been the most effective measure in reducing the spread of the virus. Others expressed frustration and disbelief at the extent of the measures being used particularly the Test and Trace system, invasion of privacy and potentially being penalised for sharing information. There was evidence to suggest that Black people were more likely to be fined for lockdown breaches. Again, this was linked to a mistrust of the government and how data is used by the government.

Despite some criticism, churches, alongside community groups and charities were felt to have provided a greater level of practical support to individuals. Services such as befriending telephone calls, delivering food parcels and grocery shopping were the key support that was recognized.

In terms of the impact of COVID-19 and the lockdown, there were concerns about access to healthcare due to the cancellation of appointments and closure of non-essential services. There were frequent conversations about the mental health impact and such concerns have been highlighted in various forms throughout the lockdown. Similarly, participants spoke about disparities within the class system, poverty and deprivation in relation to the Black population and the impact of such inequalities. There was a sense of Black people being blamed and stigmatised throughout the pandemic. How can Black people be blamed for a virus that supposedly came from China? Participants wanted more information and scientific evidence regarding the statement that Black people are more susceptible to COVID-19. There were also views that additional support should be provided to those who are identified as vulnerable, including appropriate PPE.

The added pressures of home schooling were mentioned as a stress enhancer and exposed the difficult situations that parents found themselves in. One participant spoke of not having enough laptops to ensure all their children could log on to online classes and being called by teachers reporting that their children are not logged on. Without greater access to more laptops the parent was left to choose which of their children could log on and who has to miss out on education. There was also reference to the indirect consequences of school closures and community settings, including the murder of Keon Lincoln who was killed at a time when he should have been at school.

The murder of George Floyd was mentioned frequently when discussing world events amongst young people in the 18-24 age range. It was argued that its significance was heightened because people were in lockdown and the video of his death was seen more than it would have otherwise. On 21st April 2021 a guilty verdict of second-degree murder was returned on the former police officer who knelt on George Floyd's neck. There were some conversations about world events that had highlighted injustices and racism in its

many forms - individual, institutional and structural. Participants spoke of the impact this had had on them during an already difficult time.

For many the racial disparities in the death figures were reflective of the position of people from Black African Diaspora communities. Many participants had been affected by the death of a loved one, friend or colleague and many commented on the inability to grieve in the usual way due to the lockdown rules and restrictions which has often prevented cultural traditions and practices being followed. Some were concerned about the longer-term impact this might have on the grieving process.

There were mixed opinions on the COVID-19 vaccination. A large number of participants were of the opinion that there had not been enough information provided about the vaccine and expressed a need for more clarity, particularly in relation to the science behind the vaccine and long-term effects on health. Many participants feared unwanted side effects and being used as guinea pigs. This could be understood in the context of past unethical experimentation on the Black populations by companies that are now at the forefront of promoting COVID-19 vaccines. Whilst these experiments and studies have taken place outside of the UK, they can undoubtedly contribute to mistrust and engagement with healthcare services. Therefore, the government, scientists, researchers and healthcare professionals must be mindful of this social history and legacy.

There were some participants who had already received the vaccine or were intending to receive the vaccine. Most participants did not think the vaccination should become compulsory due to freedom of choice and the wider implications. There were some hidden conflicts that arose within families and institutions as a result of the vaccine roll out. Some families were divided especially when the issue of vaccinating an elder was being considered. The conflict of an elders' wishes to be vaccinated could be at odds with those of the person taking responsibility for their welfare who may be sceptical of the benefits and motives around the vaccines.

Many believed the vaccine would be compulsory in specific situations, or through the backdoor by making it difficult to operate normally without a vaccine. For example, travelling to other countries, attending public events, going to school, and working in a specific field such as health care and public services.

There were mixed views around compliance and adherence to rules and restrictions. Lack of adherence was linked to mistrust of the government, the impact of poverty and the importance of spending time with family as a Black individual. There was reference to government representatives not modelling the required behaviour. When considering life after lockdown, most expected life to be different, but were not sure about how it would be different. There were concerns about financial difficulties for individuals, wider organisations and the growing divide between the rich and the poor. The extension of the furlough scheme had been positive for some but what lies ahead once it finishes is unknown. Others were hopeful that life would change for the better due to new insights, realisations and priorities following a life in lockdown.

Finally, suggestions were made for government and policy makers. Most of these were to better utilise and support community groups and organisations who might be better placed to engage with and support the Black community. Similarly, many felt information would be better received and understood if given by people they can identify with and relate to, such as community leaders, religious leaders and Black healthcare professionals who

are not too far removed from the community. Participants also wanted clearer, accurate information and were keen to learn about the evidence behind policies and decisions that are made by the government and policy makers. The presentation of information was also considered, with a need to avoid jargon but also to convey the message in a way that is not condescending.

Given the issues with poverty and deprivation, there was a request for more support within the community including educational support and resources to reduce the inequality between the Black population and their white counterparts. This also included more research into issues affecting the Black community and addressing these issues to help rebuild the trust and belief that government and healthcare systems are invested in the Black community and achieving positive change. The BAME acronym was referred to as too generic and highlighted the value of more effectively differentiating between different ethnicity groups so that guidance can be better tailored to the needs of those specific groups. This was also highlighted in a recently commissioned government report (Commission on Race and Ethnic Disparities, 2021).

Black majority churches and church leaders.

Religion was not an identified variable when conducting the research but during the course of the research, there were emerging comments and activities that required us to relate to the role of Black majority churches during the pandemic. The role of the Black led churches was questioned in that there was a feeling that they had been too quiet about the lockdown and vaccination. There was criticism for a perceived lack of direction for the congregations regarding taking vaccines, but a number of West Midlands based Black majority church leaders and Black clergy took it upon themselves to either publicly share their individual decision about taking a vaccine or shared a picture of themselves being vaccinated. However, most stopped short of directing the Black African Diaspora communities to take the covid 19 vaccine.

In January 2021 Rev Owen Uriah was interviewed on BBC Midlands Today. This was following the hosting a mobile vaccination unit at the ground of his church.

“I’m not pro vaccine and I’m not anti-vaccine. I think individuals have to make up their own minds and our role is to help them get the right information to do that”

When questioned about the interview he explained:

“I don’t take notice of the YouTube and Facebook videos, the way I see it if you want advice about your car you go to a mechanic so with covid you should be getting information from the qualified health professionals”

He acknowledged that even hosting a mobile unit had caused rumblings.

Reverend Eve Pitts shared a YouTube video giving her personal reasons for deciding to come to the conclusion of taking the vaccine when it is offered. However, she stopped short of telling the Black community to take the vaccine when it is offered as it remains a personal choice.

Community rights activist Reverend Dr Desmond Jaddo shared a picture of himself taking a vaccine as did Bishop Dr Joe Aldred.



Courtesy of Dr Joe Aldred

“

The vaccines are the best way to protect ourselves from COVID and offer a way out of the pandemic. Most importantly, they are safe. I've had mine and I urge you to get yours when you're invited to.

Bishop Joe Aldred, Bishop Church of God of Prophecy



In April 2021, Dr Joe Aldred went a step further and was amongst the first Black church leaders to publicly urge the Black community to take the vaccine when offered. He gave an opinion as to why there was no collective response from Black majority churches:

“I don't have a congregation, but I understand why some pastors have stopped short of telling their congregations to take a vaccine when offered. A Pastor with a congregation seeing that their flock is divided over an issue, is more likely to show by their own example rather than telling members what to do”

“As for the challenges around the Covid vaccines, I understand the community's skepticism, but when there is a virus around, if there is an antidote for that virus it's a good idea to take that antidote. No medicine is 100% safe, not even cough medicine for which the notes include various escape clauses and possible side effects”

“What is good for one is good all for and the less we take the vaccine the greater the chances of the virus seeking out those who are vulnerable. I believe taking the vaccine is good for us on a whole”

There were mixed views as to the role played by Black majority churches during the pandemic. Whilst for some the Black churches played a positive role on a wider scale there was criticism for not sending a clear message to parishioners. A criticism of the Black led churches was a feeling from young people that there was a lack of leadership in helping congregations to decide on the question of whether people should take a vaccine. There was also criticism in that churches closed and few offered any kind of support outside of a Zoom style service which was not appropriate for many of the older congregation who did not have digital access.

Black majority church leaders were unable to put on a united message regarding the vaccines which some saw as a failure, however, the church movement by its nature has divisions so it is perhaps ambitious to expect a totally unified position. For some church

leaders they make clear that in their opinion there is no theological reason not to take a vaccine, but for some the reluctance is a direct result of the interpretation of biblical verses including references to the Book of Revelations which talks about the Mark of the Beast and notions of the end of days leading to interpretation of the jab being associated with the Mark of the Beast.

The neutral approach was supported by the Bethel foundation one of the largest Black majority church networks in the country. It decided to host a webinar using health professionals including doctors and nurses within its congregation to discuss COVID-19 and clarify the pros and cons of taking a vaccine with the intention that balanced advice and information would help individuals to make informed decisions. YouTube removed the video for violating community standards. There was no explanation or warning, and the video was only reinstated after an appeal against its removal succeeded.

Should I take it COVID-19 vaccine and the Church

<https://www.youtube.com/watch?v=G7ozpnZwRk4>

An incident in Birmingham where a Black majority church was secretly visited by undercover police checking on congregation numbers did not go down well and created more tension. It was met with the wrath of the pastor whose anger was clear for all due to the sanctity of the church being disrespected.

Police raid on Black Church

<https://www.birminghammail.co.uk/news/midlands-news/birmingham-church-leaders-fury-police-19049031>

Some felt that Black churches could have done more during the lockdown:

“Marcus Rashford made the government change policy and do U-turns and he is a footballer yet the Black churches have not impacted” (age range 25-40)

Some recognized that the churches had been the victim of restrictions to the point that even where special services were allowed there were bans on singing and numbers were greatly reduced.

“What is the word...but we are the most investigated in terms of restrictions such as you can't sing, you know, whereas we only meet a few hours, if that, a few moments a day on a Sunday and I just, I just I, this is my personal opinion, if you don't mind I just feel that there's been a lot of emphasis on restrictions of church” (age range 55-64)

Muslims leaders were quicker to seek and get answers to key questions that could hinder attempts at vaccination so were quick to allay fears regarding pork or fetal tissue being in the vaccine. The chief officer of the Yemeni Community Association in Sandwell directly implored fellow Muslims to take the vaccine when offered and assured followers by declaring the vaccine halal thus removing barriers to taking the vaccine. Whether the religious interventions have been effective in getting more African Diaspora communities from Christian and Islamic faiths to take a vaccine would need specific investigation.

The pandemic within a global context

There have been large differences in COVID-19 death figures per head of population and it can be argued that they are related to the actions taken by the respective governments. Criticisms of the UK government were that they acted too late to lock the country down, allowed air travel to continue enabling the virus to be brought in from other countries and allowed mass gatherings such as the four day Cheltenham horseracing festival which attracts 250,000 race goers leading to the view that they put profit before people.

In contrast, countries which managed the virus by quickly putting firm restrictions on travel and movement in place such as New Zealand had a lower rate of deaths per head of population, less than 1% compared to the UK 2.88%.

There are high levels of vaccine hesitancy within African American communities and public health agencies have responded by working with barbershops and stylists as a route into African American communities to get the health messages out about COVID-19 vaccines and address the misinformation that circulates.

Vaccine Apartheid

This issue of COVID-19 vaccine availability adds to concerns when looking at the richer industrial nation's vs the poorer nations. The idea of there being a vaccine apartheid is developing, where if you are in a country where vaccines are highly available, feelings of relative safety can be restored quite quickly. However, if you live in a country where vaccine availability is lower, the time taken to get back to normal can be much longer.

Covid Vaccination Access (COVAX) is a coalition with the aim of promoting equal and fair access to COVID-19 vaccines. The United Nations identified that there was evidence of the richer nations purchasing COVID-19 vaccines in higher numbers than they actually need. This further emphasises the divide as most richer nations are white majority populations and most poorer nations are Black or non-white majority populations. For many, this was evidence that even in times of a global pandemic access to finance can determine who gets and who does not get vaccinated. In May 2021, the latest COVAX report indicated that they were 153,000,000 vaccines short of their target and put this shortage down to a combination of richer nations purchasing the available vaccines and the impact of the so called "Indian/Delta" variant of COVID-19 sparking a new outbreak in India and other parts of the world including the UK. This has affected the capacity to manufacture and distribute to other parts of the world.

Covax and vaccine hoarding

<https://www.youtube.com/watch?v=jmslUkqUUfM>

The gap between the developing countries and the G7 richest countries that make up the richest industrial democratic economies was highlighted by the recent summit where the G7 leaders agreed to donate one billion vaccines. However, according to the World Health Organisation 11 billion vaccines were required. The idea of vaccine apartheid poses a moral dilemma based on need and vulnerability. For example, how can it be that a fit and healthy 18 year old in England is vaccinated before a vulnerable 70 year old in Kenya?

“There was a really great quote which I really agree with to sum up all of what I’m saying and that was, we’re all in the same storm but we’re not all in the same boat” (age range 25-40)



The Follow-Up

Changing attitudes towards a vaccine

An added element to the original research study was to explore whether participants had changed their position in regard to COVID-19 vaccines. This was because over time, casual discussions with colleagues and others indicated that the views held in January to February 2021 may not be as relevant in March to April 2021. The original UK Household Survey took place when no vaccine had been developed or approved. When we conducted our initial survey, between December 2020 and February 2021, a vaccine had not only been developed but had been approved for use. Given this, one may have expected a higher level of respondents indicating that they would take a vaccine.

Trusted voices and prominent Black individuals

We were mindful that since the vaccines were approved there had been enhanced efforts to promote taking up the vaccine directed towards Black communities. The trusted voices campaign involved as part of a strategy to increase vaccine uptake amongst Black, Asian and minority ethnic communities, the government launched the trusted voices campaign where local authority public health departments and NHS strategy and engagement teams were directed to identify community organizations and prominent individuals from these communities to act as trusted voices to encourage increase in vaccine uptake. This has included attending webinars to receive information from professionals, to gain assurances and to counteract some of the misinformation available. There were also small grants to enable local groups to come up with their own schemes to increase uptake.

Videos developed included a cross party of elected African Diaspora Members of Parliament and the second was a collaboration between the NHS, Sir Lenny Henry and other Black celebrities to directly implore Black people to take the vaccine. Videos were also made by prominent members of the South Asian communities with a similar intention, and some were edited to appeal to both African and Asian diaspora communities.

Sir Lenny Henry and friends COVID-19 vaccine appeal

<https://www.youtube.com/watch?v=0mKYnTZvIUM>

A range of recordings were used to target Black, Asian and other communities.

<https://www.itv.com/news/2021-01-25/new-video-aims-to-reach-ethnic-minority-communities-hesitant-over-covid-vaccine>

A follow-up with a smaller sample of the original respondents was carried out to help identify what proportion of participants might have changed their mind about taking a

vaccine. We were not only interested in logging levels of change but the reasons for that change. We felt this was crucial as policy makers need to know if what they are promoting is effective in influencing behavioral change.

Adding the follow-up had the disadvantage of extending the research beyond the original target deadline, however, we strongly believed that the added benefit of understanding the level of change and the reasons prompting this change would enhance the research benefit. The follow-up enabled us to gauge the level of change between the interviews, focus groups and surveys two months later. We found that two months after the initial interviews, focus groups and surveys, changes in views about the vaccine could be detected across a range of respondents. Change from those who were very unlikely or unlikely were the most noticeable.

Procedure

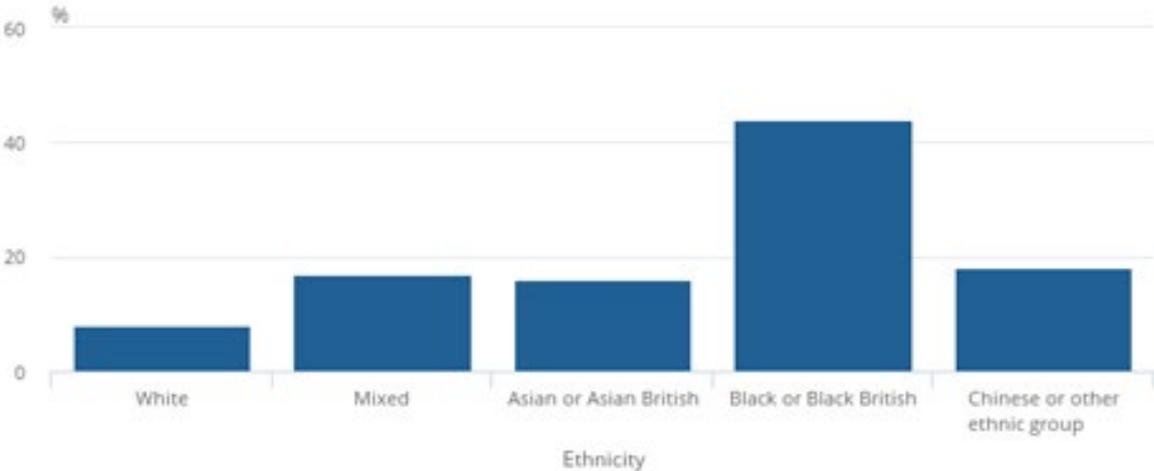
The follow-up was carried out over a period of four weeks between 15th March and 16th April 2021 with a total of 64 of the original 119 respondents – just over 50% of the original number of participants. This took place in the form of a short telephone call to remind them of the original response. Contact was made with participants who had expressed vaccine hesitancy in their original responses – this being that they were unlikely, very unlikely or undecided about taking the vaccine. Respondents were asked if there had been any change in their views towards the vaccines and if so, the reasons for these changes.

Changes in attitudes towards the vaccine March to April 2021

We decided to take our enquiries another step further by identifying if there had been any changes since we interviewed at the start of the year. A follow up household lifestyle survey indicated that Black or Black British remained the most vaccine hesitant group.

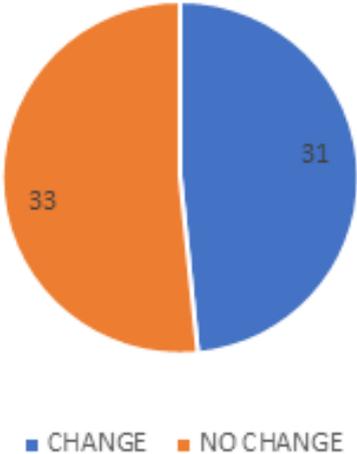
Figure 3: Over 4 in 10 Black or Black British adults reported vaccine hesitancy; this was highest of all ethnic groups

Ethnicity, Great Britain, 13 January to 7 February 2021

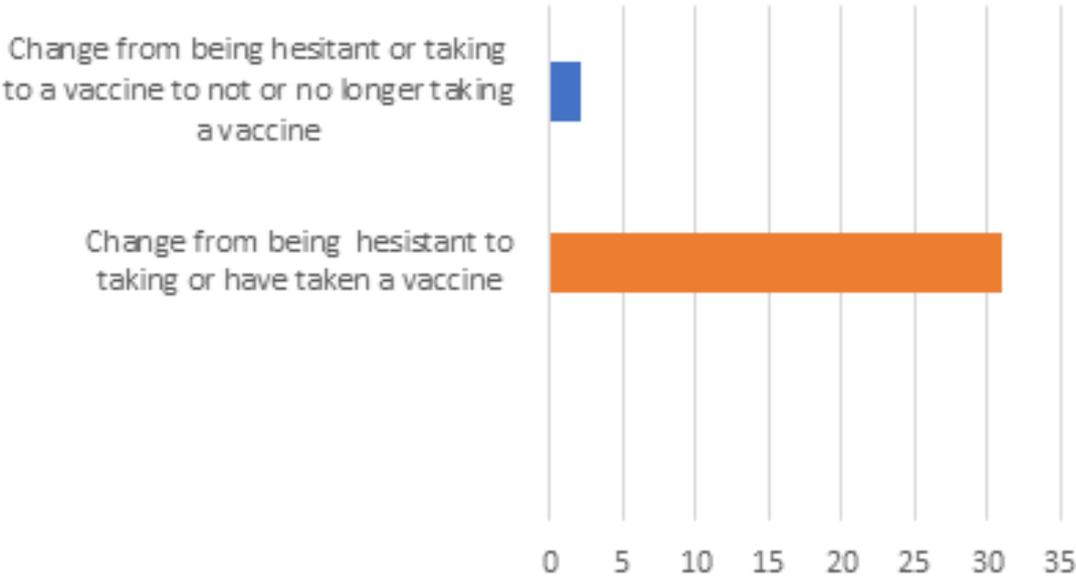


Out of the 64 respondents, 33 (52%) had not changed their minds, whilst 31 (48%) had changed their mind. Of those that had changed their mind about taking a vaccine, 29 had changed from being vaccine hesitant to now being likely or very likely to take the vaccine or had already received their vaccination.

Change in Attitudes to Vaccines March - April 21 N = 64



Direction of Change in Taking a Vaccine N = 33



Changes towards taking a vaccine

The majority of those who reported a change at the follow-up had changed their position from being hesitant to taking the vaccine to being likely to take the vaccine or receiving the vaccine. Pragmatism based on perceived and potential restrictions on life such as travel abroad, and work requirements were the most common cited reasons for people changing from being vaccine hesitant to taking a first vaccination or deciding to take a vaccine. A key factor cited was knowing someone who has taken the vaccine. Protecting self and family were also mentioned as reasons for changes towards taking the vaccine.

The role of Black celebrities was a minor factor in the decision-making process. Shaun Wallace of the popular ITV quiz program *The Chase* agreed to be filmed taking his COVID-19 vaccine and spoke of his personal reasons for taking it but implored people to do their own research and make their choice emphasising that no one should be forced to take it if they did not want to.

Shaun Wallace taking a vaccine

<https://www.facebook.com/hmichelleJohnson/videos/4130889536922080>

There was only one reference to the targeted NHS campaign of Sir Lenny Henry being a reason for now wanting to take a vaccine. There was no mention of the cross-party video of Black MPs again imploring the Black community to take the vaccine as an influence. One respondent who had previously informed the researchers that they were not taking it and had gone on to receive their first vaccination by follow-up said:

“If you need to travel it seems that you need a certificate of vaccination, so it is best to have it. A lot of people who said they were not having it are having it now. There are places that you can’t go into unless you have it and the government are saying that a lot of care workers aren’t having it, so they are going to make it compulsory. They announced it today” (23rd March 2021; age range 65+)

For others the influence of family and friends and trusted knowledge was the key factor in making the change:

“After speaking to other Black people who have taken the vaccine, family and friends. My auntie was a nurse and forensic scientist aware of my health issue (sickle cell) and being diabetic said it was ok for me to have. There was nothing in it bad for me” (age range 55-64)

For others time to think and observe was a key factor behind the change:

“Yes I’ve taken the first dose. The reasons are I blocked out all noise and broke it down to two decisions. Either I take it may or may not get side effects, but these can be managed etc blood clots, pain and cold and flu symptoms. These are known and I can manage these at home with meds or at hospital. Or I decide not to have it may or may not get covid but if I do which is likely because I have not been vaccinated and have sickle cell and go to the hospital regularly and mix with lots of different people at work and socially then I don’t know how covid will affect me and it’s likely because of my sickle cell I would become very unwell and end up in intensive care” (age unknown)

“I thought about it logically and not get swayed by community views, not be swayed by internet, and other people had first vaccine I’ve had some people say I didn’t think you would have it. The majority of people around me are having it. Don’t look at what I’m going through to make your decision. I’ve now had my first jab” (age unknown)

Changes away from taking a vaccine

There were a small minority of changes from being either undecided or being likely to take a vaccine to now deciding not to take a vaccine. This was affected by emerging concerns particularly about the Astra Zeneca vaccine and its connection to blood clots. One respondent who was previously undecided and had changed to unlikely to take a vaccine at follow-up said the following:

“Astra Zeneca blood clot story has cemented my view as I have had blood clots before and can’t risk being one of those who has side effects” (age range 55-64)

Another commented on their lack of trust due to the information about vaccine safety changing:

“I don’t trust the NHS, first said Oxford was safe then said it is not, now offering something else. A risk of blood clot for people with sickle” (age range 41-54)

Enough is enough! No more vaccine testing in Africa. We wont allow **X**! We are not animals in Africa, test it in your country. WE'RE DIFFERENT FROM OUR ANCESTORS!
DEAR AFRICANS, LETS MAKE THIS GO VIRAL!





Medical Racism and Mistrust

A number of those who were very unlikely to have a vaccine when offered cited the infamous Tuskegee experiment as a basis for not trusting what the government and medical profession's offer of a vaccine. The concept of white majority government exploiting poor Black communities within a medical context is represented by what happened during this experiment. This was a clear indication of medical racism and classism where 399 Black African American men from the south were falsely informed that they were being given medicine to cure syphilis when they were in fact given a placebo all under the knowledge and approval of the US Government who wanted to see the long-term effects of syphilis.

More shocking was what happened after where the same official in the Tuskegee experiment went one step further to Nicaragua and oversaw the extension of the Tuskegee experiment by actually injecting syphilis into poor country dwellers.

Abhorrently, penicillin was discovered to be an effective treatment for syphilis in 1947. Despite knowing this the medical professionals involved in the experiment continued to falsely inform participants that they were being treated despite some of the participants dying from the impact of the disease. Ultimately the US Government were complicit in their deaths. It was not until a whistle blower's intervention in 1972 caused it to be stopped.

Trust/Tuskegee

<https://www.youtube.com/watch?v=4W21-nfMMow>

Answers to Frequently asked questions about Tuskegee

<https://www.cdc.gov/tuskegee/faq.htm>

Extension of the Tuskegee experiment in Guatemala where poor were injected with syphilis

<https://www.youtube.com/watch?v=nha9MsSSKvE>

The then US President Bill Clinton eventually issued a formal apology (16 May 1997), which was 25 years after the ending of the “experiment”.

The more recent case of one of the COVID-19 vaccine providers Pfizer's work in Nigeria on meningitis has a familiar pattern of people of the Black African heritage and low economic circumstances being exploited for experimental purposes under the guise of free health care.

Pfizer and Nigeria

<https://www.theguardian.com/world/2011/aug/11/pfizer-nigeria-meningitis-drug-compensation>

On the 5th April 2020, two French scientists were slammed for proposing that Africa should be used as a testing base for yet to be developed COVID-19 vaccine. This at a time when the French population had 93,733 confirmed cases compared to 9,310 confirmed cases in Africa as a continent covering 54 countries.

<https://www.youtube.com/watch?v=w2GzVKGN1W4>

It was felt to be unethical to conduct a clinical trial in a place where there is comparatively little no disease or there is nothing to test for. The Director General of the World Health Organisation Dr Tedros Adhanom Ghebreyesus said the remarks went against solidarity. Africa cannot and will not be a testing ground for the vaccine. The scientists were criticised for racist and post-colonial thinking.

World Health organisation and others criticise the idea of covid experimentation in Africa

https://www.youtube.com/watch?v=rOPACr_0S10

“When we’re in a time when everybody’s already anxious or talking about it and this is what I’m trying to say about the Black community, we always have to find ways to come together and rise above the struggle. The violence. The injustice is that that we’re handed, and it is there are disparities, where we’re having to do this at greater length than any other group and I believe that is because Black community is the most degraded and I would say the most hated of all groups in the world”.

“I think as a lot of people have said already. It’s our faith with there is something that is really grounded, the Black community which is FAITH”

Birmingham responses to targeted campaign with Tru Powell and Paulette Hamilton

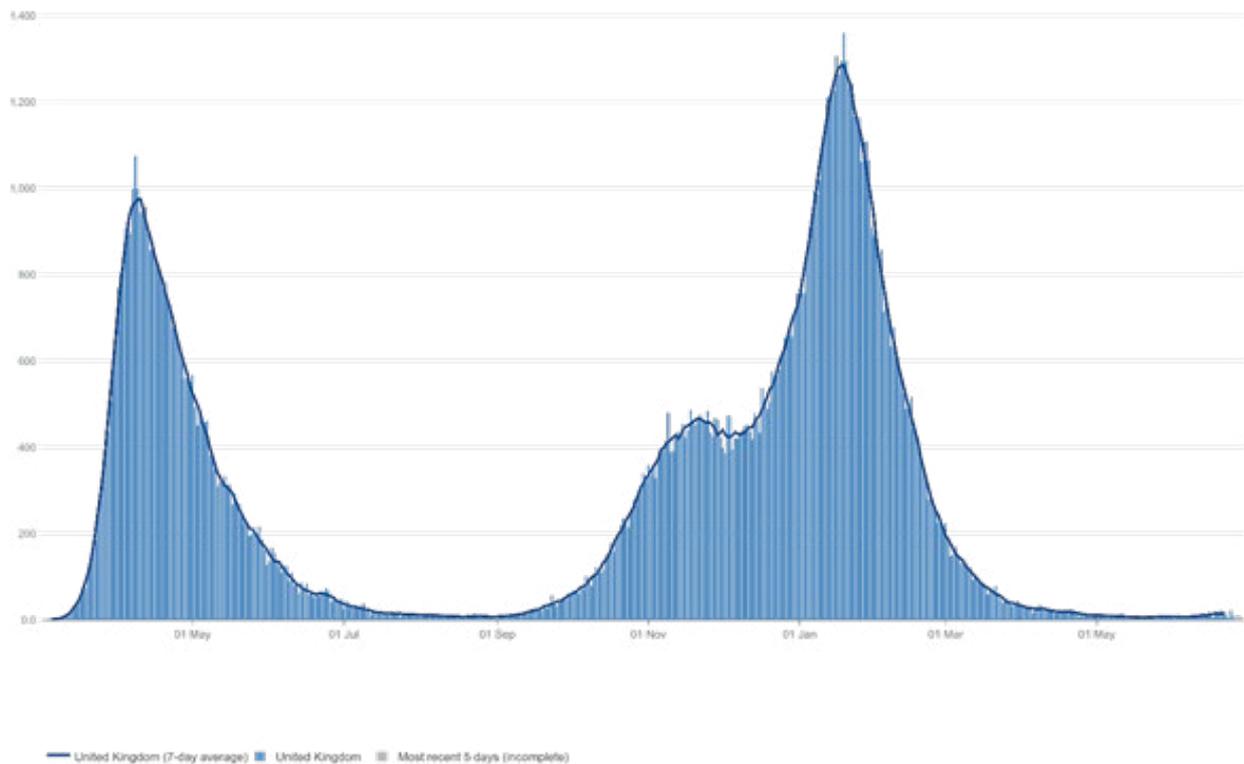
<https://www.youtube.com/watch?v=aZrQ2D7R8NA>

<https://www.youtube.com/watch?v=rR0XzuffhMBQ>

20,000 deaths seen as a good outcome

<https://news.sky.com/story/coronavirus-experts-once-said-20-000-deaths-was-a-good-outcome-so-where-is-the-uk-headed-now-11978609>

Government reporting on coronavirus has moved in emphasis away from daily and total death figures towards daily and total vaccination figures. The issue of the death figures need to be part of any review given that the nation had been informed to expect up to 20,000 deaths which has now been exceeded more than sevenfold. The figure below shows the level of covid deaths up to the end of June 2021. The lowest daily death figure before the lifting of the first lockdown and reopening of hospitality with the Eat Out to Help Out was 3 deaths, all pre vaccination.



The Royal Society of Medicine COVID-19 Webinar series 15 looked at ethnic minorities and revealed Black and minority ethnic staff having experienced poor management, being exposed to working with no PPE and indicating a culture of fear if they complain. This echoed the findings of an ITV survey of 2,000 doctors and nurses receiving 4,000 comments identifying feelings of being disproportionately put on covid wards. Slowness of management to respond to concerns around PPE and fear for their jobs if they make a complaint. PHE guidance was not reflecting World Health Organisation guidance which was more robust. In the discussion Dame Donna Kinnair Chief Executive and General Secretary of the Royal College of Nursing identified a lack of responsibility in the management structure and a bullying culture where people aren't speaking up. Where people were working with appropriate PPE we were not seeing the racial disparities.

Royal Society of Medicine COVID-19 Webinar series 15

<https://www.youtube.com/watch?v=VCc7rAZWTBE>

Institute of fiscal studies death rate of NHS staff more than twice that of whites

<https://www.youtube.com/watch?v=8L7s7Z6nECQ>

From the Cradle to the Grave: The Extent of Racial Inequality / Disparity and the wider context

For some the disparities in covid death rates and vaccine hesitancy is symptomatic of wider inequality that are evidenced in health, employment education housing and the criminal justice system. To help put this into context we have identified a number of key areas from starting life and through life to illustrate the context in which Black people of the African Diaspora communities live. Whilst it is recognised that there are many individuals from African diaspora communities who have achieved great levels of achievement in their chosen fields it remains that for the majority of people from African diaspora communities, the general experience of areas that have a known impact on health and wellbeing including health, education, wealth mental health work and the criminal justice system consistently show worse experiences / outcomes when compared to white British and most other groups. For some the overrepresentation of African Diaspora communities amongst the death figures reflects a wider pattern of inequality experienced in society.

Key facts

Below is a snapshot of how Black African diaspora communities are experiencing services and areas that impact on health and life chances to reveal how the pattern of inequality in health outcomes for Black African Diaspora communities extends beyond health to wider social and economic areas. Anti-Black racism as a public health issue could be an explanation as to why when matched for age, occupation, social class and other variables Black people of the African diaspora poorly when compared to white counterparts.

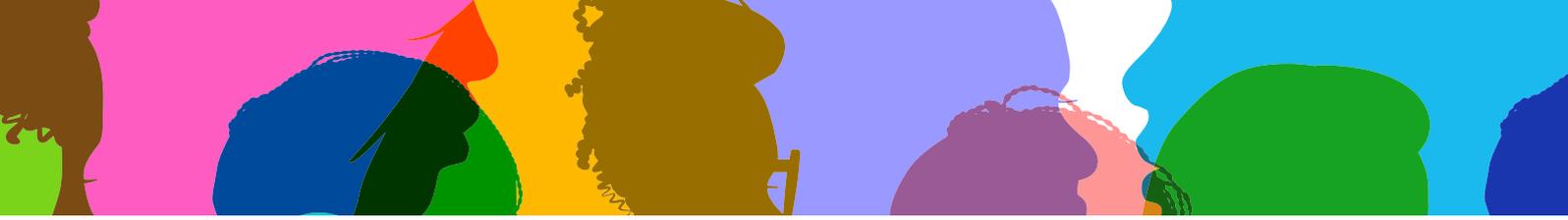
1. Black women have a higher rate of miscarriage than other groups; 43% higher than that of white women.
2. Black Caribbean's and Black Africans have the highest rates of infant mortality.
3. Black Caribbean women are more likely to suffer miscarriage.
4. Black women are reported to be four times more likely than white women to die in pregnancy or childbirth.
5. Black Caribbean are 1.7 times more likely to die as a result of being undertreated for pain. Research has shown the existence of racial bias in pain assessment and treatment due to beliefs that date back to slavery, that Black people feel less pain and have higher pain thresholds (Hoffman et al., 2016).
6. Black African 3.5 times more likely to be key workers.
7. Black Caribbean pupils are still 2.5 times more likely to be permanently excluded from school than white British children.
8. Black Caribbean and mixed white/ Black Caribbean communities had the highest rates of permanent school exclusion with the exception of Gypsy/Roma and traveller Irish groups,
9. Black male graduates experience 17% lower pay compared with white male graduates, even after controlling for factors such as type of work, personal characteristics and background (Henehan and Rose, 2018).
10. There is a rising risk of psychosis in Black Caribbean groups which is estimated to be nearly seven times higher than in the white population.
11. Detention rates under the Mental Health Act during 2017/18 were four times higher for people in the 'Black' or 'Black British' group than those in the 'White' group.
12. Suicide rates are higher among Black African Diaspora men when compared with their white British counterparts.
13. Over the period 2005 to 2019, the percentage of young people in custody who were Black more than doubled from 12.5% to 27.8%

14. Finding that Black men were more likely than their White counterparts to experience a psychotic disorder in the last year.
15. The Black group had amongst the highest levels of individuals (77%) earning £26800 or less alongside Bangladeshis and Pakistanis

Mental Health

The Adult Psychiatric Morbidity Survey (APMS) identified mental health concerns for Black African Diaspora communities (Black / African / Caribbean / Black British people) f
Source Mental Health Foundation

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



Conclusion

This research was carried out in response to the COVID-19 pandemic, the COVID-19 vaccination programme and the reported vaccine hesitancy amongst the Black population. We felt that further exploration and better understanding of the reasons for vaccine hesitancy and other matters relating to the COVID-19 pandemic and life during lockdown was highly important. This is because effective public policy requires not only being able to answer questions but also to ensure that questions are asked in an appropriate way and that we truly understand the reasoning behind the answers that are received.

The information obtained from speaking to people within the local Black African diaspora community was thorough and provided a good insight into the subject area. The research showed that participants in the 65+ age range were more likely to take a vaccine, whilst participants in the 18 to 24 age range showed the highest level of hesitancy.

Male participants had a higher level of indecision around taking a vaccine. At follow-up, the people who had decided to take a vaccine were more influenced by knowing friends and family who had had a vaccine, and the belief that there would be a negative impact if they did not take it, such as further restrictions on daily living such as travelling abroad.

Throughout the research project, we identified underlying mistrust of the wider socio-economic political system, which can be linked to negative experiences of racism which is evidenced by racial inequality.

Our main observations are outlined below:

- COVID-19 vaccine hesitancy was higher across the board than previously reported in the General Household Survey in June 2020, but the evidence of change carried a large swing towards Black African diaspora communities now changing from hesitancy to taking the vaccine.
- Decisions to vaccinate against COVID-19 were as much based on pragmatism as it was on the protective role of the vaccine. Respondents felt that whilst it may not be compulsory to have a vaccine it will be difficult to get back to “normal” or effectively operate in the new normal if you are not vaccinated particularly for work and travel.
- Decisions not to vaccinate were related to distrust in the authorities in particular the speed of the development of the vaccines and no data for long term side effects. Vaccine hesitancy is linked to the let’s wait and see approach.

The reporting of racial disparities in COVID-19 deaths was considered at times to lack sensitivity and served to exacerbate pre-existing fear and distrust, effectively putting up barriers to important messages by further alienating Black African diaspora communities from engagement with public health messages and preventative actions.

- A high proportion of those interviewed were living on their own and there was little mention of overcrowding as a factor for those interviewed. This had been one of the general explanations given for high COVID-19 infection rates within BAME groups, which may not apply to Black African Diaspora communities.
- Having one or more underlying health conditions has been identified as a key factor in how individuals experience COVID-19 and their recovery. A total of 72% of the 92 respondents to the question on health conditions had one or more underlying health conditions which if replicated in the wider population could be a factor in the racial disparities in death from COVID-19.
- Some respondents working in health services were critical of the NHS in regard to feeling pressurised to work on COVID-19 wards with little or no PPE. Given the higher number of people from Black and ethnic minority backgrounds working within key worker roles, this issue should be investigated to identify the role that pressure to work with little or no PPE may have played in the higher death rates for people within the Black African diaspora community and other ethnic minorities.
- Regionally and locally structured investment in Black African diaspora led groups appears to be lacking. A lack of structured public investment in Black led African diaspora community groups is evident in that there is no Black African diaspora led national infrastructure organisation that were able to lobby and advise the government on issues of concern. The absence of collective voices from Black African diaspora communities endorsing government guidance or opposing is indicative of the low status created by consistent historical and present inequality.
- The use of all-encompassing terms such as BAME being used to “cover” Black African Diaspora communities does little to support effective health planning for health prevention protection and management for this particular group.
- For Public Health Services to recognise and accept that vaccine hesitancy is not new in African Diaspora Communities and to be innovative and patient in helping people to change their view and understanding.
- Ensure health professionals and those responsible for public health have a better understanding of factors that can hinder engagement. For example creating spaces for those with lived experiences to deliver training for workers on racism and its impact.
- Only a very small proportion of respondents directly benefitted from the furlough scheme.
- The use of all-encompassing terms such as BAME being used to “cover” Black African Diaspora communities was not a term that was embraced by the respondents it was also felt it did little to support effective health planning for this particular group.
- Respondents in the health services supported criticism of the NHS regarding feeling pressurised to work on covid wards and with little or no PPE.



Recommendations

The announced Public Enquiry into the government's handling of the pandemic needs to:

- Critically examine the reasons for the disparity between the expected death rates announced in April 2020 of 20,000 and the current number which is in excess of 130,000.
- Specifically address the discrepancy in death rates for Black NHS staff and social care staff and specifically seek to understand the reasons for the higher levels of death recorded in African Diaspora communities for example interviewing existing workers as to their treatment during the pandemic.
- Examine what has been the reason(s) for people changing their minds about taking a vaccine so they can better target resources and more effectively engage with Black African diaspora communities.

Government, Local Authorities and the NHS:

- A full Audit of local authorities and NHS Clinical Commissioning Groups to establish the level of investment in Black African Diaspora community groups and businesses by way of service contracts and grants which will enable the government to understand the lack of infrastructure.
- A higher level of acknowledgement of the impact of historical and current experiences of racism as a factor linked to vaccine hesitancy in Black African diaspora communities is required for government and public health bodies to effectively engage with Black communities. A proactive engagement approach needs to be embedded within public health bodies, rather than them only being seen to be engaging when there is a problem, which opens them up to criticism.
- The government and public health bodies need to recognise and accept that some individuals simply do not trust “the system” and will not want to take a vaccine under any circumstances. Vaccine hesitancy is not new amongst African diaspora communities and public health authorities will need to revise their expectations of vaccine uptake; the pre-existing evidence suggests low vaccine uptake in other areas of health has been a known factor for years within the Black African diaspora population. Public health bodies must be innovative and patient in helping people to change their view and understanding.
- Public health attempts to increase vaccine uptake should be focussed on providing compelling evidence as to the benefits of taking a vaccine without appearing to be pestering individuals or worse still forcing it upon people. Our evidence shows that most people want to be able to make their own choice and do not want to feel coerced into taking a vaccine.

- By knowing that there are individuals who are undecided and the reasoning behind the indecision they will be better equipped to target for a positive outcome. More extensive research on vaccine hesitancy broken down by employment status, housing status, relationship status will give indications of how best to target health messages.
- Given that a lot of hesitancy was based on the speed of vaccine development, government and public health authorities need to put a much greater emphasis on explaining the development of the COVID-19 vaccines. This includes reasons why it has been possible to develop and approve a vaccine in such a comparatively short period of time by emphasising the co-operation of pharmaceutical companies and the levels of investments from private and public funds, which has enabled the greater speed of development without compromising safety. Fully explaining the fundamental difference between normal vaccine development which is often cloaked in secrecy and competition between pharmaceutical companies, and the development of COVID-19 vaccines which has been the result of co-operation and collaboration will go some way to eliminate a major concern regarding the speed of the COVID-19 vaccine development.
- Provide accessible information and ensure people can access clear, independent information that is factual to improve results rather than simply telling people to take a vaccine when it is offered.
- Our evidence suggests that beliefs about the role of social media negatively impacting on the decision to vaccinate is overplayed. We found that people across the age ranges tended to rely on their family and national news sources. Few cited social media as a source they relied on for information.
- Public health authorities should allow time for friends and families to ‘wait and see’ given the observed levels of mistrust and negative experiences. Our evidence shows that the biggest factor for those who were vaccine hesitant becoming vaccine positive was familiarity with others, particularly friends and family members who had taken the vaccine and hearing their stories of how it has impacted them.
- Accept that not everyone will take a vaccine and not to chastise or ostracise those who choose not to. People from Black African diaspora communities who decide not to take the COVID-19 vaccine are not necessarily anti-vaxxers.
- Health professionals and those responsible for public health must have a better understanding of factors that can hinder engagement. For example, creating spaces for those with lived experiences to deliver training for workers on racism and its impact.
- To effectively engage with Black African diaspora communities, public health officials need to be able to differentiate between barriers created by false news and those that exist due to factual historical racism exercised within health care coupled with current evidence of racial inequality. These issues remain key barriers to full engagement.

- One size does not fit all; public health messages require a combination of diversified and specific approaches tailored to sub-groups within Black African diaspora communities. A more tailored approach to public health campaigns, taking on board what drives vaccine hesitancy, for example in different age groups, younger age groups, or those with underlying conditions, will be more effective than using the same blanket message.
- Who delivers the message matters; it is important that those giving the message reflect the target community to give reassurance and build trust. Black African diaspora communities are more likely to trust messages that come from professionals from their own community. Making better use of Black African diaspora representation amongst the experts and information givers may help to maximise opportunities to develop trust. If messages are coming from people who look like those they are targeting and have the professional knowledge, this will improve the chances positive changes particularly around hesitancy.
- For effective engagement with Black African diaspora communities, government and public bodies need to review their level of investment in Black African diaspora led organisations including not for profit organisations, focussing on grants and contracts held, followed by immediate investment to address identified shortfalls. Greater investment in Black led African diaspora community organisations will help to increase resilience and enable better responses to such crises.
- Effectively engaging with Black majority churches opens a door to huge numbers of Black African diaspora communities and it should be a priority for government and public health officials seeking meaningful change. Public Health bodies should recognise the importance of strategically engaging with Black majority churches as a route into developing work to address racial disparities in health and devise a commitment to ongoing work including church-based health promotion programs targeting health inequalities.
- Public health authorities should allow time for friends and families to wait and see given the observed levels of mistrust and negative experiences. Our evidence shows that the biggest factor for those who were vaccine hesitant becoming vaccine positive was familiarity with others, particularly friends and family members who had taken the vaccine and hearing their stories of how it has impacted them.
- Government, public bodies and businesses should use this opportunity to develop fundamental change because going back to normal is not something that many people from Black African Diaspora communities want. Effectively engaging with Black majority churches opens a door to huge numbers of Black African diaspora communities and it should be a priority for Government and public health officials seeking meaningful change.
- Greater investment in Black led African Diaspora community organisations to increase resilience and better respond to such crises. Providing accessible information and showing a greater level of acknowledgement of historical medical racism and model changed behaviour to get trust.
- Future surveys looking at this and other issues around vaccination should include an undecided category and allow for respondents to give a reason for their responses and a follow up.

- Our evidence suggests that beliefs about the role of social media negatively impacting on the decision to vaccinate is over played. We found that people across the age ranges tended to rely on their family and the national news sources. Few cited social media as a source they relied on for information. Public health authorities will need to revise their expectations of vaccine uptake within Black African Diaspora communities given that there is pre-existing evidence to suggest the low vaccine uptake in other areas of health has been a known factor for years.
- Public health planners and policy makers need to increase their knowledge and understanding of the impact of racial inequality and experimentation leading to mistrust of official announcements. By doing this it will lead to better planning to address covid and other health concerns. They will need take several further steps to understand the reasons behind the decisions that people make.
- The blanket BAME approach to public planning for health and other public services is likely to be ineffective due to the lack of specificity and understanding of how policies affect specific communities. The government's independent Commission on Race and Ethnic Disparities recommended that this term should no longer be used.

The NHS should develop national guidelines for recording racial disparities and patient ethnicity to have better ethnic data on their patients including ethnicities being recorded on death certificates.

- Research on the impact of COVID-19 and the lockdown with children under 18 to use as a basis for intervention and support programs in a post lockdown period of restoration. Government and public health bodies need to put a much greater emphasis on explaining the difference in the creation of the COVID-19 vaccines, in particular the unprecedented level of investment which has enabled the greater speed of development without compromising safety that sets COVID-19 vaccines apart from traditional vaccines. Fully explaining the fundamental difference between normal vaccine development which is often cloaked in secrecy and competition between pharmaceutical companies and the development of COVID-19 vaccines, which has been the result of co-operation and collaboration will go some way to eliminate a major concern which is speed of the COVID-19 vaccine development.
- Racism by way of pressurising Black staff to work with little or no PPE protection within the NHS should be investigated as a factor in higher death rates for African diaspora NHS staff covid death rates.

Future research:

- Future surveys looking at this and other issues around vaccination should include an undecided response category and allow for respondents to give a reason for their responses and a follow up to help capture any change.
- Vulnerability to COVID-19 from Black African diaspora communities should be investigated further and may be understood within the context of high levels of comorbidities reported by respondents, particularly hypertension, diabetes, sickle cell and asthma.
- More extensive research on vaccine hesitancy or indecision broken down by employment status, housing status, relationship status will give indications of how best to target health messages.
- Conduct research on the impact of COVID-19 and the lockdown with children under 18 to inform future planning intervention and support programs for young people.



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Angela Mahabeer
Deska Howe
Georgina Walker
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Revd Owen Uriah
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Bishop Landell
Sandwell African Caribbean Mental Health Foundation
Organisation for Sickle Cell Anaemia Research Sandwell
Cape Community Day Care
Bethel United Apostolic Church UK

And most importantly all the participants who gave their time and energy in responding to some searching questions.

APPENDIX 1



Black, Covid and in Lockdown: In Our Own Words.

A qualitative community-based research project focussing on Sandwell and the surrounding areas of the West Midlands

Participant Information Sheet

West Bromwich African Caribbean Resource Centre is a Community based charity with a long track record of supporting African Caribbean communities in the areas of health education social care and welfare training and employment. We want to find out the thoughts and experiences of Black people of African Diaspora heritage and what they have experienced during the lockdown. People who fit this category may be called black British African Caribbean dual black and white heritage We would like to invite you to take part in our community research project. This participant information sheet is designed so that you understand why this research is being conducted and what your participation may involve. Please take the time to read the information below carefully and decide whether you wish to partake. If you would like further clarification on any of the following, please do not hesitate to ask.

What is the purpose of the study?

This research aims give a voice to black people and their experience of the lockdown and the impact of covid on them. It seeks to get your views on emerging patterns around being black differences in experiences around covid and individual perceptions of why patterns are emerging. It seeks to understand if government guidance is effective, if the key messages are being understood, what are the key information sources and what is influencing behaviour of covid to explore the understanding of COVID-19

Why have I been invited?

As a member of the black African diaspora community, you fit the category of who we want to hear from. We want to obtain your insight into the perceptions and experiences of COVID-19 and the lockdown held by yourself and other members of the Black community.

Do I have to take part?

No, taking part in this study is completely voluntary. You can refuse to answer any question during the interview and choose to withdraw entirely at any point. If you change your mind after taking part, you can withdraw permission of your data being used within 7 days of your interview. In this case, your data, recording and consent form will be destroyed.

If you change your mind after the interview, please do inform us by emailing shane.ward@wbacrc.org.uk

What will taking part involve?

With your permission, you will take part in an interview that will involve a series of open-ended questions for you to provide responses to, relating to you and your views of the Black community's perspectives of COVID-19. This interview will either be conducted online (e.g. using Zoom) or by telephone, in which case you will need to provide your contact number. The interview is expected to last for approximately 30-60 minutes depending on how much you have to say, and the audio will be recorded so it can be transcribed afterwards. If you are taking part in a focus group the meeting will last approximately one hour.

What are the possible benefits of taking part?

Participants will be given a reward to the equivalent monetary value of £20 as a recognition for their time, paid 7 days after the interview / focus group has taken place. The research will help decision makers understand how future plans need to consider the experiences of black people from the



African diaspora. We hope the information provided may help reduce the impact on the Black community. However, by providing your insight into your community's perceptions of COVID-19, this study's findings can be used for further research into how your community can be helped to minimise the impact of COVID-19.

Will taking part in this study be kept confidential?

All interview and data will be confidential and anonymised so nobody can be identified. In the report it may read "one participant said....."

Data collected will help us to know how many people were interviewed and categorise answers e.g "younger people interviewed felt"

A data collection sheet will be sent before the interview for you to complete and return. It can be done as part of the interview or by completing the link to the data collection survey. We will need to record the session so what is said can be transcribed (written up) and the zoom software is able to do this quickly.

We can provide a transcription of the one to one interviews but not the focus groups.

You should receive a consent form when you are invited to the interview which we will require to be completed and returned. If you do not you will be asked to give your consent on the day.

The audio-recording of your interview will be deleted once it has been transcribed. Transcriptions will be kept.

Data obtained from this study will be securely kept on a password-protected WBACRC remote server or a password protected Zoom account.

Will I be reimbursed for taking part?

You will receive a recognition payment equal to the value of £20 for your time.

What will happen to the results of the study?

You can request to receive a copy of your transcript within 7 days of your interview. To do so, please email: shane.ward@wbacrc.org.uk

Findings will be used to produce a report that will be disseminated to stakeholders research article that may be published in a healthcare journal. You will not be identified in any report.

Who can I contact if I have further queries?

Please Shane Ward by emailing Shane.ward@wbacrc.org.uk if you have any other queries.

What next if I want to take part?

If you decide to partake in this research, please confirm via email above **(insert your email address)**. Please also keep this information sheet for future reference. You will be sent a consent form to complete and return and an interview will be arranged for a suitable date.

Who can I contact if I have a complaint about the conduct of the study?

You may be contacted as a quality assurance check after the interview
Any complaints can be directed to Shane Ward.

APPENDIX 2



Black, Covid and in Lockdown Data Collection Survey

1. What age category do you belong to?

- 18-24
- 25-40
- 41-54
- 55-64
- 65-79
- 80+

2. What are your current living arrangements?

- LIVING ON MY OWN
- LIVING WITH A PARTNER
- LIVING WITH A PARTNER AND CHILD/CHILDREN
- LIVING WITH A CHILD/CHILDREN BUT NO PARTNER
- LIVING IN A MULTIGENRATIONAL HOUSEHOLD CHILD PARENT GRANDPARENT
- LIVING IN A HOUSE/FLAT SHARE
- LIVING BETWEEN HOME AND PARTNER

3. Which of the following best describes your current relationship status?

- Married
- Widowed
- Divorced
- Separated
- In a domestic partnership or civil union
- Single, but cohabiting with a significant other
- Single, never married
- Living between your own home and your partner's



4. What is your current housing status?

- OWNER OCCUPIER NO MORTGAGE
- OWNER OCCUPIER WITH MORTGAGE
- RENTED PUBLIC OR SOCIAL HOUSING
- RENTED PRIVATE ACCOMODATION
- SQUATTING
- HOMELESS

5. Do you have any disabilities or underlying health conditions? If so tick all that apply

- CANCER
- STROKE
- DIABETES
- HIGH BLOOD PRESSURE
- CORONARY HEART DISEASE
- ASTHMA OR OTHER RESPIRATORY CONDITIONS
- SICKLE CELL
- THALASSAEMIA
- LUPUS
- VISUALLY IMPAIRED
- SPEECH IMPEDIMENT
- HEARING IMPEDIMENT
- OBESITY
- PARPLEGIC
- QUADRIPLEGIC
- OTHER
- NONE
- Other (please specify)



6. What is your current work/ study situation? Tick all that apply

- FURLOUGHED
- WORKING FROM HOME AS NORMAL FULL TIME
- WORKING AT BASE AS NORMAL FULL TIME
- WORKING REDUCED HOURS
- MADE REDUNDANT
- YOU HAVE CLOSED YOUR BUSINESS
- YOUR BUSINESS IS ON REDUCED HOURS
- WORKING FROM HOME ENFORCED
- WORKING PART TIME
- UNEMPLOYED
- RETIRED
- VOLUNTEER
- STUDENT
- SELF EMPLOYED

7. What is your sex?

- Male
- Female
- Other
- Other (please specify)



8. Do you work, own a business or volunteer in any of the work areas listed below. Tick all that apply

- HEALTH - NHS OR PRIVATE HOSPITALS, CLINICS, COMMUNITY HEALTH
- SOCIAL CARE - CARE HOMES DOMICILIARY CARE
- TRANSPORT LOGISTICS
- FOOD RETAIL DELIVERIES
- EMERGENCY SERVICES POLICE, FIRE, AMBULANCE OR RESCUE
- SANITATION MAINTENANCE AND CLEANING SERVICES
- TRAFFIC MAINTENANCE
- ENERGY
- NONE
- OTHER
- Other (please specify)

9. How do you define your heritage/ identity?

- BLACK AFRICAN
- BLACK AFRICAN CARIBBEAN
- BLACK AFRICAN AMERICAN
- BLACK AFRICAN EUROPEAN
- BLACK BRITISH
- MIXED AFRICAN AND WHITE EUROPEAN
- MIXED BLACK CARIBBEAN AND WHITE EUROPEAN
- MIXED AFRICAN AND ASIAN
- MIXED AFRICAN AND ARABIC
- AFRICAN AND SOUTH AMERICAN
- BLACK OTHER
- Other (please specify)

10. What is your postcode? (First part only, for example for B70 6LY write B70)

DONE

APPENDIX 3



SEMI-STRUCTURED INTERVIEW GUIDE



Title: Black, Covid and in Lockdown: In Our Own Words

Date:

Time:

Place: MBC area e.g Sandwell Birmingham Solihull Coventry Warwickshire Walsall Dudley Wolverhampton Staffordshire

One to one or focus group:

Interviewer:

Interviewee: allocate an id

INTRODUCTION SCRIPT

Introduce the study

We are looking to get the views and experiences of black people of African origin which includes Black Britons, West Indians, people from various Caribbean islands and people from the mainland African continent who are living in the borough of Sandwell and the surrounding areas of the West Midlands. The research is in relation to being 'Black, Covid and in Lockdown: In Our Own Words'. This is a piece of community-based research and is not academic. We hope the findings will inform decision makers of the distinct views and experiences of Black People regarding covid and the lockdown which will need to be considered when making major decisions.

This is independent community research coming from the Black African diaspora community organisations who recognize the need for Black voices to be heard and its role in helping this happen.

The project has been supported by a grant from the National Lottery Community Fund

Introduction

Confirm your **name position and your organization** and that you are a delivery partner on this project operated by of West Bromwich African Caribbean Resource Centre a registered charity specializing in Health Education and Social Care. **If you are directly engaged by WBACRC to work on this project please state that you are an independent interviewer working on behalf of WBACRC.**

Inform interviewees/ respondents of confidentiality and anonymity (for focus groups this is part of the ground rules)



Black, Covid and in Lockdown: In Our Own Words.

A qualitative community-based research project focussing on Sandwell and the surrounding areas of the West Midlands

Participant Information Sheet

West Bromwich African Caribbean Resource Centre is a Community based charity with a long track record of supporting African Caribbean communities in the areas of health education social care and welfare training and employment. We want to find out the thoughts and experiences of Black people of African Diaspora heritage and what they have experienced during the lockdown. People who fit this category may be called black British African Caribbean dual black and white heritage We would like to invite you to take part in our community research project. This participant information sheet is designed so that you understand why this research is being conducted and what your participation may involve. Please take the time to read the information below carefully and decide whether you wish to partake. If you would like further clarification on any of the following, please do not hesitate to ask.

What is the purpose of the study?

This research aims give a voice to black people and their experience of the lockdown and the impact of covid on them. It seeks to get your views on emerging patterns around being black differences in experiences around covid and individual perceptions of why patterns are emerging. It seeks to understand if government guidance is effective, if the key messages are being understood, what are the key information sources and what is influencing behaviour of covid to explore the understanding of COVID-19

Why have I been invited?

As a member of the black African diaspora community, you fit the category of who we want to hear from. We want to obtain your insight into the perceptions and experiences of COVID-19 and the lockdown held by yourself and other members of the Black community.

Do I have to take part?

No, taking part in this study is completely voluntary. You can refuse to answer any question during the interview and choose to withdraw entirely at any point. If you change your mind after taking part, you can withdraw permission of your data being used within 7 days of your interview. In this case, your data, recording and consent form will be destroyed.

If you change your mind after the interview, please do inform us by emailing shane.ward@wbacrc.org.uk

What will taking part involve?

With your permission, you will take part in an interview that will involve a series of open-ended questions for you to provide responses to, relating to you and your views of the Black community's perspectives of COVID-19. This interview will either be conducted online (e.g. using Zoom) or by telephone, in which case you will need to provide your contact number. The interview is expected to last for approximately 30-60 minutes depending on how much you have to say, and the audio will be recorded so it can be transcribed afterwards. If you are taking part in a focus group the meeting will last approximately one hour.

What are the possible benefits of taking part?

Participants will be given a reward to the equivalent monetary value of £20 as a recognition for their time, paid 7 days after the interview / focus group has taken place. The research will help decision makers understand how future plans need to consider the experiences of black people from the



African diaspora. We hope the information provided may help reduce the impact on the Black community. However, by providing your insight into your community's perceptions of COVID-19, this study's findings can be used for further research into how your community can be helped to minimise the impact of COVID-19.

Will taking part in this study be kept confidential?

All interview and data will be confidential and anonymised so nobody can be identified. In the report it may read "one participant said....."

Data collected will help us to know how many people were interviewed and categorise answers e.g "younger people interviewed felt"

A data collection sheet will be sent before the interview for you to complete and return. It can be done as part of the interview or by completing the link to the data collection survey. We will need to record the session so what is said can be transcribed (written up) and the zoom software is able to do this quickly.

We can provide a transcription of the one to one interviews but not the focus groups.

You should receive a consent form when you are invited to the interview which we will require to be completed and returned. If you do not you will be asked to give your consent on the day.

The audio-recording of your interview will be deleted once it has been transcribed. Transcriptions will be kept.

Data obtained from this study will be securely kept on a password-protected WBACRC remote server or a password protected Zoom account.

Will I be reimbursed for taking part?

You will receive a recognition payment equal to the value of £20 for your time.

What will happen to the results of the study?

You can request to receive a copy of your transcript within 7 days of your interview. To do so, please email: shane.ward@wbacrc.org.uk

Findings will be used to produce a report that will be disseminated to stakeholders research article that may be published in a healthcare journal. You will not be identified in any report.

Who can I contact if I have further queries?

Please Shane Ward by emailing Shane.ward@wbacrc.org.uk if you have any other queries.

What next if I want to take part?

If you decide to partake in this research, please confirm via email above **(insert your email address)**. Please also keep this information sheet for future reference. You will be sent a consent form to complete and return and an interview will be arranged for a suitable date.

Who can I contact if I have a complaint about the conduct of the study?

You may be contacted as a quality assurance check after the interview
Any complaints can be directed to Shane Ward.



Suggested ground rules for focus groups

- 1. Only one person to speak at a time no talking across each other**
- 2. Own your statement i.e. we are interested in your experiences and views**
- 3. Allow others to speak (the facilitator will need to be observant to encourage participation of all.**
- 4. Make use of the hand icon so you know who wants to speak**
- 5. Respect each other even if you disagree with what and individual may have said we are not here to judge but to listen and record**

Comments will not be identifiable and Names will not be used

In form the interviews that we will need to hold the transcripts of the interviews centrally if you would like a transcript of your interview, please inform shane.ward@wbacrc.org.uk

Statistical data

For statistical purposes you will be are required to complete a data sheet that tells us how representative those completing the survey are. Age, marital status, etc.

All responses are anonymous and individuals will not be quoted

Rights of the Interviewee

Inform interviewee of right not to answer a question if they do not wish to

Inform interviewee of the right to stop the interview at any time without jeopardy

You have the right to withdraw your consent within **7 days of the interview**

Consent

We are required to get consent (verbal or written) to participate send out the the consent form prior to the interview using email and attach it to the zoom invite. So that you can see if consent has been given. If it has not been returned ask for verbal consent don't forget to record the verbal consent being given.

Get consent for audio recording this will be in the consent form but if missed please get the consent

Before starting the interview gain verbal consent of it has not been given. Remember to switch off your video camera. They may want to do this too so only the name appears on the screens



QUESTIONS

The questions are be open ended questions which allow a more of a conversation

THOUGHT AND FEELINGS

1 Can you tell us about your first **thoughts and feelings** when it was announced that there was going to be a lockdown? What things did you have to do to adjust to your new life in lockdown ?

Prompts: Working from home, put on furlough lower income. more time with family, home schooling increased caring responsibilities for parents

2 How has the lockdown **affected** your work / study life / Home/ Family Life / Health and well being

INFROMATION SOURCES AND KEY MESSAGES

3 **What or who did you rely on to inform you about COVID-19 and how did this affect your behavior?**

Prompt

(At home college work social media WhatsApp Facebook Instagram, mainstream news family and friends)

4 **Thinking about the information about covid, which sources do you feel have been most reliable sources of information and which were least reliable and why do you say this?**

GUIDEANCE AND SUPPORT

5 **What are your views about the guidance and support available from**

Prompt (E.G STAY AND HOME KEEP YOUR DISTANCE PROTECT THE NHS SAVE LIVES STAY SAFE HANDS FACE SPACE)

Central Government

NHS

Local Government

Third sector Charities community group

Places of worship/ faith-based groups/ family members

(YOU WILL NEED TO GET THEM TO SPECIFY WHICH AREA THEY ARE TALKING ABOUT)



6 THERE HAVE BEEN LOTS OF MEASURES TAKEN OVER THE LOCKDOWN PERIOD In your opinion what has been most effective and what has been least effective in managing the spread and impact of Covid 19

Prompts (Track and Trace, strict lockdown, reduction in numbers of gatherings hand washing PPE straplines tier areas)

Focus groups may be given a poll to vote on what is the most effective and what is the least effective

Impact

7 During the lockdown some people have reported feelings of isolation loneliness stress and anger. If any of these have applied to you what has been the reason for those feelings.

Prompt: Has there been any thing that has happened during lock down that has added to these feelings

WORLD EVENTS

8 There has been some major incidents throughout the world are there any particular incidents that affected you if so what where they and what impact did it have on you physically mentally emotionally? Probes: George Floyd, Windrush

DEATH AND BEREAVEMENT

9 Deaths attributed to covid has impacted many individuals and families What impact if any has it had on your life and what have you being doing to help you cope how have you tried to cope.

Prompts and expectations

Remember this is a sensitive question so be prepared emotionally. Prompts Not being able to grieve, not being able to support grieving families / friends not being able to attend a funeral no pre funeral rituals like nine nights

EMERGING PATTERNS PRODUCED BY RESEARCH

The emerging patterns of lockdown suggest a number of things including

Young people at more risk of unemployment

Churches and places of worship locked down

Restrictions on funerals numbers and social gatherings

Students at higher risk of developing mental health problems



SEMI-STRUCTURED INTERVIEW GUIDE



Older people and black people at a higher level of risk for covid 19 and over represented in the death figures

Older people being at most risk

Increased domestic abuse

Children from low-income families at risk of falling behind academically

People avoiding hospital appointments or having appointment cancelled

10 How has the lockdown affect your work/ study life/ Home/ Family life / Health and well-being

(Encourage them to expand delayed/ appointments cancelled child care restrictions child contact problems)

Attitudes to Vaccines / Medical Responses

11 What are thoughts about the vaccines

12 Do you think taking a covid 19 vaccine will become compulsory for all ?

Should it be compulsory for all or just some

13 At this moment in time How likely are you to take a vaccine

Very likely Likely Undecided Unlikely Very Unlikely

The same question based on what you think the majority of black people would say

14 At this moment in time How likely do you think most black people are to take a vaccine

Very likely Likely Undecided Unlikely Very Unlikely

and what are the key reasons for your answer

15 What was your understanding of the advice and guidance given by the Government?

16 Do you think the Black community generally understand the advice given?

Compliance / Behavior

17 Do you think black people in general are more or less likely to comply with restrictions imposed and why do you say this?

18 What if anything has altered your view on covid 19 and being in lockdown How if any has the lockdown changed your behavior? what has influenced this change?

19 What would you say is the key message(s) / areas that government and policy makers need to consider when looking at black people and Covid 19 and the future.



We are coming towards the end of the interview just a couple more questions

20 What are your expectations of life after lockdown?

21 Is there anything else that you would like to say about your experiences of being black covid and in lock down?

Once they have stopped talking confirm that this is the end of the interview.

Stop the recording and Turn back on your camera

CLOSING

Concluding Statement

Script Thank you for taking part your responses have been very helpful

This information will be collected analyzed and contribute to a community report Black Covid and in Lockdown: In Our Own words that when completed will be accessible from West Bromwich African Caribbean Resource Center. If you would like to see the report once it is completed, please email shane.ward@wbacrc.org.uk Re Black Covid and in lockdown: In our own words Report

Thank you for your time

Reiterate

Confirm that they have the right to withdraw within the next 7 days

Interviewees/ respondents will be eligible for an acknowledgement reward 7 days after the completion of the interview / focus group providing there has been no request to withdraw their consent.

Collect demographic information if it has not been provided SEND A LINK OR SHARE A HARD COPY

What happens next

Inform them of what will happen after the interview

Recording and transcript is anonymized checked and sent to for analysis and report writing ensure anonymity

Their responses will be collated and formed into a report. The report will pick out any emerging themes.

Provide contact information if they need to contact the organization about the study . inform them that they may get a quality assurance email or telephone call to ask if the interview was conducted appropriately.



SEMI-STRUCTURED INTERVIEW GUIDE



Shane.ward@wbacrc.org.uk

Ask them if they would like the opportunity to be involved in other research areas that may arise

If they do, inform them we will need to retain some contact information and that they may be contacted for future research.

Inform them that they can withdraw within 7 days and their interview will be deleted

They will be eligible for a recognition voucher or cash payment to the value of £20 if they want to donate it they can

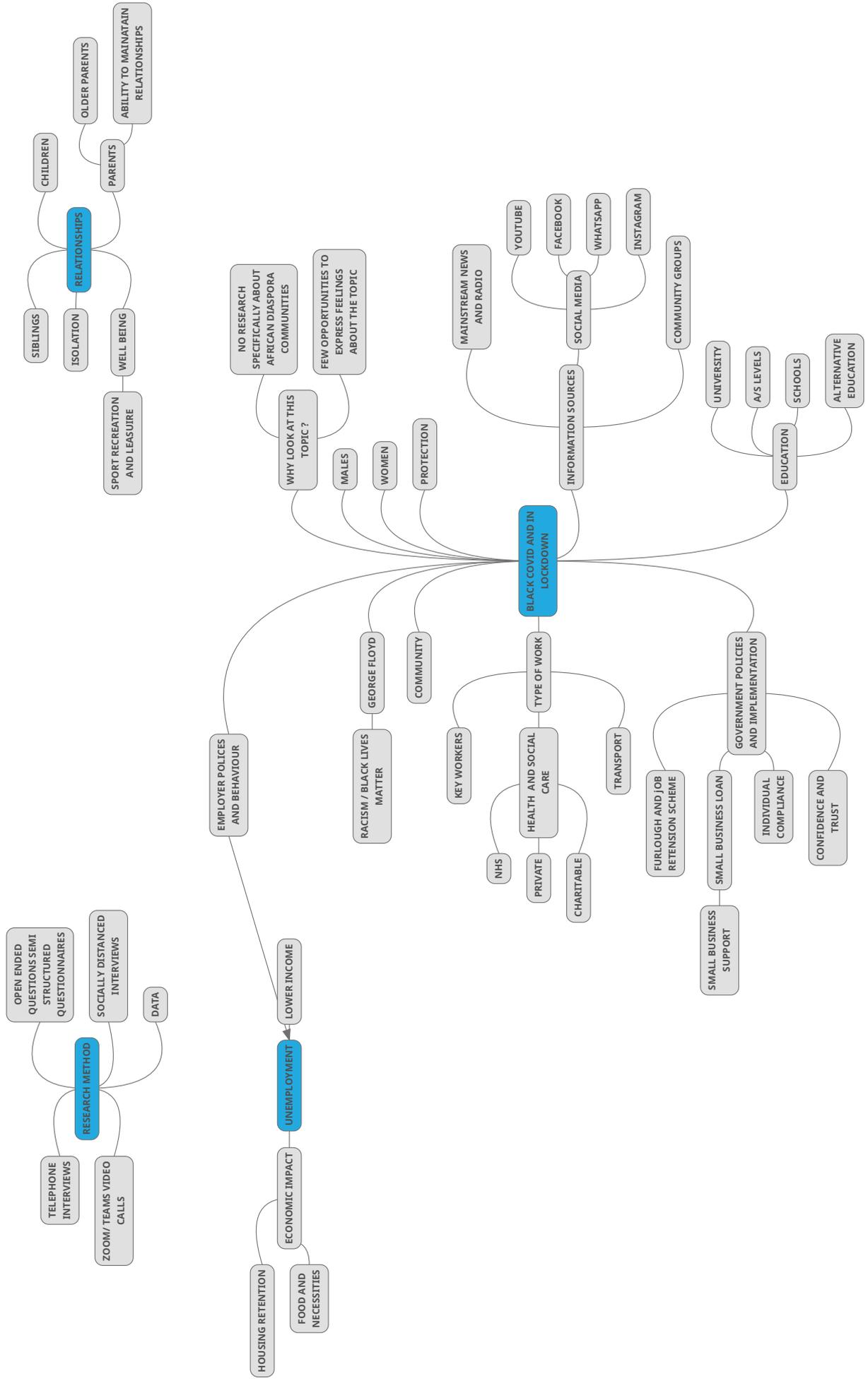
Thank them for their time once again

Remember to help you, you can get the interview schedule on your screen as you ask the questions

APPENDIX 4

APPENDIX 5

Black, Covid and in Lockdown : In Our Own Words. Mind Map





Black, Covid and in Lockdown: **In Our Own Words**

A community based research on the thoughts,
feelings and impact of COVID-19 and the lockdown
on Black african diaspora communities in
Sandwell, West Birmingham and the wider West Midlands

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