

**CANCER AND WELLBEING DURING THE COVID-19 PANDEMIC
BLACK CARIBBEAN AND BLACK AFRICAN
CANCER PATIENTS AND CARERS**

Report to BME Cancer Communities

Dr Sophia Skyers, Consultant Researcher (BA Hons, MA, MBA)

CIBS IQ Research - February 2021



BME Cancer Communities

BME Cancer Communities is a charitable incorporated organisation (CIO)
registered in England: No 1182806.

Table of Contents

Acknowledgements	3
Foreword by Rose Thompson, Chief Executive	4
1. Introduction to the report	6
2. Context and background	7
3. Health inequalities	8
4. The analysis of the results of the survey	9
5. Case studies	22
a) Gary Dean – Patient Case Study (African)	22
b) Paula Edwards – Patient Case Study (Caribbean)	24
c) Winston Carrington – Patient Case Study (Caribbean)	25
d) Pauline Johnson – Patient Case Study (Caribbean, South America)	26
e) Lesburne Easie – Carer Case Study (Caribbean)	28
6. Conclusion and recommendations	30
Appendix – Sources	32

Acknowledgements

We would like to say a huge thank you to all of the patients and carers who took the time to complete the survey, and also to those who provided the case studies that are featured in the report. We are profoundly grateful to all of you as this project would not have been possible without your involvement.

The support of the following organisations has also been key to the completion of this report, through their signposting of cancer patients and carers of cancer patients to the survey, in their active promotion of it, and in supporting the initiative in other ways. They are as follows:

- ACLT (African Caribbean Leukaemia Trust)
- Jamaica Diaspora UK
- CANSURVIVE UK
- Sistas Against Cancer
- Friends and Bredrins (FAB)
- The West Bromwich African Caribbean Community Centre
- The Hugh Dwyer Inspirational Foundation
- African Health Policy Network
- Nottingham Hospital's Charity
- African Women's Empowerment Forum
- Mojatu

Thank you all again!

Foreword by Rose Thompson, Chief Executive



There are in excess of 220 different types of cancer and this is not a case of abstract figures. They impact populations in many ways. As you turn the pages of this report, you will learn that some cancers are more likely to disproportionately impact specific ethnic groups, and at much younger ages than is the case for the population generally. The impact of the COVID-19 pandemic has served to place an even brighter spotlight on Black and Minority Ethnic (BME) health inequalities.

BME Cancer Communities (BMECC) is a registered charity and was founded in 2010, in response to cancer inequalities among black and minority ethnic groups in the UK, manifest in many ways, including higher cancer death rates, particularly in the ageing black population from the first wave post war migration, and a higher incidence in certain types of cancer. As an organisation, we primarily focus on cancer, but have learned from our service users that health inequalities are not driven by a single issue. It was of concern to BMECC when, in early March 2020, our service users, families and friends began to report COVID-19 associated hospital admissions, followed by an increasing number of deaths within weeks of hospitalisation. BMECC also noted that ethnicity was listed as a risk factor for increased mortality among the black and minority ethnic community. As an organisation, we are delighted to see that this report is embedded in a discussion about the wider social and economic factors that contribute to health inequalities. At BMECC we continue to retain and develop our advocacy, information and support role, in line with the diverse needs of our service users,

As you will see, the report includes five case studies that highlight the actual lived and diverse experiences of Black Caribbean and Black African cancer patients, and carers, living through these unprecedented times. BMECC does not underestimate what it took for Gary Dean, Paula Edwards, Winston Carrington, Pauline Johnson, and Lesburne Easie to share their experiences with us and we thank them sincerely. I would also like to thank the patients and carers impacted directly by a cancer diagnoses, who took the necessary time out to complete the survey. Add to that, our thanks to the supportive organisations that are acknowledged in the report for signposting their service users to the survey and assisting with case studies, including Jamaican Diaspora UK's Health and Wellbeing team, who also assisted with developing and evaluating the questions.

Finally, many thanks to Dr Sophia Skyers who went above and beyond the call of duty to research and author this invaluable and timely report.

A handwritten signature in black ink that reads "R.S. Thompson". The signature is written in a cursive style with a large, looped 'R' and 'S'.

Rose Thompson
Chief Executive, BME Cancer Communities

1. Introduction to the report

1.1 **The COVID-19 Pandemic:** The COVID-19 pandemic is a global health crisis that is without precedent in living memory, and one that has had and will continue to have long term social and economic consequences. While the majority of people who contract the virus will experience symptoms that are mild to moderate, the impact on the population is not a neutral one. The COVID-19 pandemic is occurring against a backdrop of social and economic inequalities and inequalities in existing non-communicable diseases, as well as inequalities in the social determinants of health. It is the case that Black African and Black Caribbean people, people from other minority ethnic groups, older people, and those with underlying health conditions such as cancer, chronic respiratory disease, diabetes, renal diseases, hypertension and so forth, have a disproportionately higher risk of adverse outcomes, including death, if they contract COVID-19. The observed inequalities in COVID-19 morbidity and mortality therefore mirror, reinforce, and compound existing health inequalities in the distribution of chronic disease, and social and economic inequalities experienced by populations at many other institutional sites.¹

1.2 It is important to make clear that ethnic classifications do not denote inviolate biological or naturally occurring categories embedded in the genetic script of individuals or groups sharing physical and or social attributes. They are socially constructed, imprecise, self-assigned classifications. As concepts they are contested, dynamic, changing over time, and they vary by country. Moreover, the 200,000-year history of humans has been one of constant migration, cultural exchange and cultural fusion, and the mixing of DNA, and therefore, illimitable diversity is not reducible to a few ascribed groupings that have been given an administrative imprimatur. The ethnic classifications that are in use are however valuable as broad social constructs as they add to our understanding of inequality based on shared social attributes and experiences, and shared connections by geographic ancestry that have biological consequences. A focus on inequality in this way is therefore critical to the framing, understanding and contextualising of risk and group disparities in health.²

1.3 In June 2020, BME Cancer Communities (BMECC) commissioned CIBS IQ Research and Consulting to undertake a small-scale open-ended survey, and to develop some case studies that explored the impact of the COVID-19 pandemic on Black patients living with a diagnosis of cancer. BMECC is a charity that provides advocacy, and a range of support services for patients and carers who have been affected by cancer. As part of its work, the organisation is seeking to understand more about the experiences of Black cancer patients and carers and their wellbeing during the COVID-19 lockdown.

¹ Bamba C, et al. *J Epidemiology Community Health* 2020;0:1–5. doi:10.1136/jech-2020-214401.

Intensive Care National Audit and Research Centre Report on COVID-19 in critical care 17 April 2020.

Bailey, Suzie and West, Michael, *Ethnic Minority deaths and Covid-19: What are we to do?* Kings Fund 30 April 2020.

Covid-19 the impacts of the pandemic on inequality, Institute for Fiscal Studies, 11 June 2020.

Platt, Lucinda, and Warwick, Ross, *Are some ethnic groups more vulnerable to COVID-19 than others?* Inequality, the IFS Deaton Review, May 2020.

² Skyers, Sophia, Kerr, Campbell, and Johnson, Pauline, *Count Me IN! Informing the future of personalised medicine from bench to bedside: A qualitative inquiry into the views of black Caribbean and black African communities on clinical trials, clinical trial enrolment, and clinical research*, The Basil Skyers Myeloma Foundation, September 2017.

1.4 **Approach:** The approach taken to the study centred on the development of a short online open-ended survey and this was supported by a brief perusal of some of the emerging literature on COVID-19 and on cancer inequalities. The approach helped to shape some of the survey themes and questions, a process that was also supported by the input of the Board of BMECC and other black and minority ethnic patient organisations into the shape and content of the questions. The approach also included the development of four in-depth case studies, three from the patient perspective and one from the carer perspective. The purpose of the case studies was to provide a vivid illustration of the experience of living with cancer, or of caring for someone with cancer during the COVID-19 pandemic lockdown, easing, and the reintroduction of restrictions.

1.5 The draft survey was piloted with a small group of patients and carers, and after further refinement, a link to the survey was housed on BMECC's website. The survey was anonymised and disseminated through black and minority ethnic patient and carer led organisations, and through formal and informal black and minority ethnic networks and forums, via email, and through hard copy and online publications between July 2020 and December 2020. There were some slight changes made to question 8 in September, after the survey had gone 'live'. Question 8 previously asked: '*are you concerned about going out now that lockdown has eased*'? The question was rephrased so that respondents were asked simply: '*are you concerned about going out*'? The slight revision was because of restrictions that were reimposed in many parts of the UK following the initial national easing of restrictions. The survey questions are set out in a table in paragraph 4.1 below. In total 146 respondents accessed the survey, 61 people responded to the survey, and 41 completed it. The report is based on an analysis of the completed surveys. The Community Surveys software only allows for analysis of completed responses. The qualitative components were analysed using framework analysis that allows for the categorisation of themes and subthemes.

1.6 **Organisation of this report:** The report is divided into six sections. The following Section 2 briefly explores the context and background to the Black presence in the UK. Section 3 explores some of the evidence of cancer inequalities among the Black population and its implications for COVID-19. This is particularly important given that the incidence of cancer increases with age, and the Black population, which is ageing, and increasing, has among the poorest outcomes from cancer and from COVID-19. Section 4 presents the results of the survey. This is followed by Section 5 which presents the four in depth case studies already discussed, and Section 6 sets out the key conclusions and recommendations.

2. Context and background

2.1 **Black migration:** The 2011 Census recorded 1,904,604 Black African and Black Caribbean residents, comprising 3% of the total population of England and Wales. This was the first UK census where, the number of self-reported Black African residents exceeded that of Black Caribbean residents at 989,628 thousand (1.8% of the total population) and 594,825 thousand (1.1% of the total population) respectively. Today, 61% of the Black Caribbean population in England and Wales arrived before 1981, and 95% of the Black African population in England and Wales arrived after 1981. There has however, always been a Black presence in the UK, dating back to Roman times, albeit in much smaller numbers than is the case today.³ The Black population is predominantly

³ David Olusoga , Black and British: A Forgotten History, Pan Books, 2016.

urban, and 60% reside in London and other larger urban conurbations including Birmingham, Manchester, Leeds, and Nottingham, and 97% are resident in England.⁴

2.2 The first large scale Black migration took place in the years between 1948 and 1970, when almost half a million people arrived in the UK, from the Caribbean. They became known as the *Windrush Generation*, named after Empire Windrush, the ship that landed on 22 June 1948, at Tilbury Docks, Essex, bringing 492 new arrivals. There were subsequent ships that sailed from the Caribbean, to the UK, including SS Auriga which arrived in the mid 1950s, and brought 1,100 passengers, as well as other migrants from the Caribbean who travelled by air. A number of *push* and *pull* factors were behind the Caribbean migratory experience. The UK had acute labour shortages in the wake of the ending of the Second World War. This included nurses needed for the nascent National Health Service (NHS), established on 5 July 1948, less than two weeks after the first Windrush passengers arrived. As well as meeting labour demands in the new NHS, Caribbean migrants, many of whom had also fought in the Second World War, were recruited to meet the demand for labour on the railways, on the buses, in armament and other manufacturing industries, and as farmworkers, electricians, cleaners, and postal workers. The attraction on the *push* side was the prospect of more employment opportunities, and a better life, as described by UK representatives who engaged in active recruitment drives in the Caribbean. For others, already enjoying a good life in the Caribbean, the opportunity to live and work in what was viewed as the *mother country*, acted as a powerful inducement.

2.3 The large-scale migration of Black Africans to the UK followed a different pattern in that it began much later than migration to the UK from the Caribbean Islands. There were many reasons behind African migration, and they included, the search for employment, higher education, and seeking asylum. The Black African population has a younger age structure than the Black Caribbean population, and migration has predominantly been from West and Central Africa and within that, principally from Somalia, Zimbabwe, the Congo, Nigeria, Algeria, Eritrea, Sudan and Sierra Leone. As with recruitment from the Caribbean, recruitment drives have also at various times, focused on Africa in order to fill vacancies in the NHS.

2.4 As well as the Black African and Black Caribbean categories in the 2011 Census, there was also a Black Other category comprising 0.5% of the total population of England and Wales and there may be some overlap, particularly with second generation Black Caribbean and Black African residents who may also identify with the *Black Other* category. There is also a Mixed White and Black Caribbean category in the Census, comprising 0.8% of the population, and a Mixed White and Black African category which comprises 0.3%. Moreover, the mixed population is now the fastest growing category ethnic category.

3. Health inequalities

3.1 **Cancer and COVID-19 inequalities:** An existing and emerging body of evidence points to poorer cancer outcomes among black and minority ethnic communities in the UK, compared with

⁴ ONS 2011 Census.

the population generally. There is also a disproportionately higher incidence of certain types of cancer among Black people compared with the population generally. It includes diseases such as prostate cancer and multiple myeloma, where the risk for both is double that of the population generally, and where the median onset age is on average, five years younger. As already explained, there is evidence that the existing disparities in cancer incidence and survival, and a higher incidence in other disease areas, for example, diabetes type 2, hypertension, and so forth, are mirrored in COVID-19 in terms of incidence and adverse outcomes.

3.2 At the heart of the planning and delivery of health services, is the principle of equality. It incorporates a focus on groups where health outcomes are not keeping pace with the general population. A review carried out by Public Health England found that the highest age standardised diagnosis rates of COVID-19 per 100,000 of the population was among those within the Black group. Moreover, while more research is needed, emerging evidence does point to a higher mortality rate due to COVID-19 in minority ethnic populations, with the Black population appearing to have the highest risk burden.⁵ There is evidence of myriad barriers to accessing health services, and poorer experiences in terms of decisions about care, treatment, and access to care and support among the black and minority ethnic population.⁶ It is in this context that promoting equal access to services, and addressing inequality is central to improving performance. The NHS Long Term Plan specifically mentions better care for people with cancer, and places a particular emphasis on improving access to personalised care and services, and tackling disparities in health and health outcomes.⁷ A report by the Social Metrics Commission found a significantly higher rate of poverty among black and minority ethnic groups and within that, found that 46% of all people living in families where the head of the household is Black is in poverty. In the case of disabled people, and this includes people who have had a diagnosis of cancer, the Social Metrics Commission found that 50% of all those living in poverty are in a household that includes a disabled person.⁸ This also has important implications in terms of the economic impact of the COVID-19 pandemic and those diagnosed with cancer and those caring for someone with cancer.

4. The analysis of the results of the survey

4.1 The questions in the survey required a tick box response, and included an open-ended text box where respondents were encouraged, but not required, to enlarge on their answers. There were 147 people who accessed the survey, 61 who partially responded, and 41 who submitted full responses. The responses were national and were drawn principally from Nottingham, followed by London, Birmingham, Manchester, and Leeds. 74.36% (29) were female and 25.64% (10) were male. There were options given for transgender and prefer not to say but none were recorded. There were 87.5% (35) Black Caribbean respondents and 5% mixed Black Caribbean respondents. The response from the African community was low, 7.5% (3) Black African, and no mixed Africans

⁵ Beyond the data: Understanding the impact of COVID-19 on BAME groups, Public Health England, June 2020.

⁶ Listen Up! Multiple Myeloma in Black Communities: An Unequal Risk Burden, The Basil Skyers Myeloma Foundation, 2015. Skyers, Sophia, Kerr, Campbell and Johnson, Pauline, Count Me In! A qualitative inquiry into the views of black Caribbean and black African communities on clinical trials, clinical trial enrolment, and clinical research, The Basil Skyers Myeloma Foundation, 2017. BME Cancer Patient Information Survey, BME Voice, 2012.

National Cancer Experience Survey, 2018.

Hear Me Now One Year On: Communities' call to action to address prostate the burden of prostate cancer in black African-Caribbean and black-African men, April 2014.

⁷ The NHS Long Term Plan, NHS England, January 2019.

⁸ Measuring Poverty 2020: A report of the Social Metrics Commission, July 2020.

were recorded despite the involvement of organisations working with African community. The age ranges of respondents were principally in the 50-59 and 60-69 age range, mirroring the fact that cancer is largely a disease of ageing, and the growing middle aged second-generation Black population, particularly within the African Caribbean group which has an older age structure than the African population. The lower response rate in the older age categories may also be to do with the fact that the survey was online.

Age	%	Numbers
16-29	7.32	3
30-39	4.88	2
40-49	7.32	3
50-59	46.34	19
60-69	26.83	11
70-79	4.88	2
80-89	2.44	1

4.2 The report is based on the full responses as Community Surveys does not have a facility for incorporating partial responses. The survey questions are set out in the table that follows:

Survey Questions	
1	Are you a cancer patient, or someone who cares for a cancer patient?
2	During the COVID-19 pandemic lockdown, did you feel that you or the person that your care for were given the right kind of information and support?
3	Do you feel that you have been listened to and that your concerns about COVID-19 have been heard?
4	Has COVID-19 had an effect on your wellbeing as a patient or as a carer?
5	Do you as a patient or the person you care for have any other health conditions?
6	Were your other health conditions given consideration within your overall care and support during the COVID-19 lockdown?
7	Have you or the person you care for missed any cancer treatments or had changes to your cancer treatment as a result of COVID-19?
8	Are you concerned about leaving home?
9	Did you have any particular financial difficulties as a result of the COVID-19 lockdown?
10	Have you accessed any financial support services as a result of the COVID-19 pandemic?
11	During the COVID-19 pandemic, have you used any local weekly food delivery services for vulnerable people?

Survey Questions	
12	<p><i>General</i></p> <p>What Part of the UK are you resident in?</p> <p>What are the first three letters of your resident postcode?</p> <p>Which Black African or Black Caribbean group do you belong to?</p> <p>What is your African or African Caribbean heritage?</p> <p>What is your gender?</p> <p>What is your age group?</p>

4.3 **Are you a cancer patient or someone who cares for a cancer patient?** 56.1% (23) said that they were a cancer patient, and 43.9% (10) said that they were caring for someone who had received a cancer diagnosis.

4.4 **During the COVID-19 pandemic lockdown, did you feel that you or the person that you care for were given the right kind of information and support?** 43.9% (18) said that they did receive the right kind of information and support, and 56.1% (23) said that they did not receive the right kind of information and support.

4.5 The analysis of the open-ended responses illuminates this further. The respondents who said they did receive the right kind of support and information explained this in myriad ways, citing phone calls from their local authorities offering a number of support services, government letters, letters from their GP practice, letters and contact from Adult Services, information and support provided by their secondary care practitioners, information and support provided by employers and voluntary agencies, as well as their own searches for information. The following remarks typify those that said that they did receive the right information and support:

'Information provided by the government via letters and telephone calls. GP, hospital and Social Services' (Patient).

'I was contacted regularly by NAH, GO, Age UK, City Council and several other groups' (Patient).

'I listened to the news and found out that I was classed as vulnerable and would have to self-isolate. I also received the government's letter stating that I had been identified as vulnerable and to follow the guidelines. I also followed the blood cancer website to get updates relating to my type of cancer. My GP receptionist would also call weekly to check on me. I also started to receive the weekly food which has some good stuff in it' (Patient).

'Support services remained in place' (Carer).

4.6 As well as information and support by telephone, emails, phone calls and printed material, the information and support provided was also practical and hands-on, empathetic in nature, and clear. This had a calming effect on both patients and carers. Moreover, in some circumstances, despite restrictions on patients being accompanied to hospital appointments because of concerns

about the spread of COVID-19, there was nonetheless some flexibility built into the system which fit with individual needs and requirements.

'Received a letter to shield followed by a phone call from my local authority checking if I needed support with getting shopping and prescriptions' (Patient).

'To be honest, I had no concerns. Every time I attended the clinic the process in place ensured all in attendance was safe. Also, when I needed support due to the distress of the diagnosis, they allowed my partner to attend alongside me and this provided great assurance for me' (Patient).

4.7 A diagnosis of cancer has a major impact on the individual receiving it, on individual family members, and on the family as a unit. The need for practical and emotional support can be particularly acute at this time, and at various stage in the patient journey. Appropriate support for patients and carers is therefore needed at a time when the experience is one of *shock, fear, isolation, anxiety, and bewilderment*. The practical demonstrations of care and support that were cited were very reassuring, and enhanced feelings of safety and security, as is clear from the following remarks:

'We received all the information we needed, and they were extremely clear' (Carer).

'I received information from my employers, breast cancer nurse, GP and support group Sistas Against Cancer' (Patient).

'I was diagnosed during lockdown and my consultant was very attentive. I was given a scan same day and biopsy appointment made for the very next day. No time was lost (Patient).

4.8 The 56.1% (23) of respondents who said they did not receive the right kind of support and information, explained this in various ways. Among the key issues were complaints that the only contact received was when appointments were cancelled, a lack of information on follow up, inconsistent information, and a lack of targeted information which they felt was too general to be of practical use. There were also difficulties cited in terms of making contact with healthcare providers. The following remarks typify those of the respondents that said that they did not receive the right kind of information and support:

'Apart from cancelling appointments, it was the only contact I received' (Patient).

'We were receiving appointment letters to be seen at the hospital clinic when all appointments were changed to telephone appointments. Consultant rang 3 hours earlier to the appointment time and did not leave a message. We did not receive verbal or written report of the latest CT scan report' (Carer).

'I never really saw any resources for carers and healthcare experts were difficult to get hold of' (Carer).

'I did not receive any different information because of cancer or shielding (Patient).

'The patient received treatment, but no support was given. This had to be requested. I, the carer, received no support at all' (Carer).

4.9 While, as explained above, there was flexibility built into the system for some patients and carers in terms of being allowed to provide support during hospital appointments, for others this was not the experience. Indeed, there were concerns about a lack of flexibility in those circumstances where patients or carers felt that they needed additional support in order to fully and effectively engage with healthcare professionals:

'Info for the vulnerable very vague and not individualist' (Carer).

'Being told only the patient goes in the room. Patient wears 2 hearing aids, issues with hearing aids and worsened deafness. No support given for disability' (Carer).

'Although initially I felt this went well during this pandemic, I feel that my concerns had not been fully addressed and I have suffered as a result' (Patient).

4.10 There were others who stated that they had received appropriate information on shielding on the one hand, but who, at the same time, felt that this was contradicted by the guidance that was issued, and exacerbated by difficulties in getting hold of staff to which questions might have been put. There were also those who felt that the focus on COVID-19 meant that information and support in relation to other illnesses or potential illnesses received scant if any attention. The result of this was heightened fear and anxiety and this in turn, adversely impacted the patient and carer experience. The following remarks exemplify this:

'Shielding information. But had problems contacting staff at hospital for follow-up action when requesting urgent Xray and scan. Misleading guidance given by some staff over telephone and face to face, had to persist to receive further investigations. Cause anxiety and frustration' (Carer).

'Very difficult communication. COVID-19 protocol wiped out concern for any other illnesses' (Patient).

'The lack of focus on my father's diagnosis was apparent and seemed to be overtaken by the health professionals' focus on COVID-19. This felt like being left to linger and getting a substandard and frustrating service' (Carer).

4.11 **Do you feel that you have been listened to and that your concerns about COVID-19 have been heard?** There were 46.34% (19) respondents who said that they did feel that they had been listened to and that their concerns about COVID-19 had been heard, and 53.66% (22) stated that they did not feel that they had been listened to and that their concerns about COVID-19 had not been heard.

4.12 The respondents who said they did feel that they had been listened too and that they did feel that their concerns about COVID-19 had been heard said that they felt that they were able to air their concerns and that these were then addressed in practical ways. There were others who cited the helpfulness and clarity of the information that they received, and the immediacy and promptness of responses to the concerns they raised. There were also those who said that they were given reassurance at every stage after expressing concerns about attending the hospital for treatment which the following remarks illustrate:

'Concerns about travel during easing, advice given and supporting letter for insurance claim provided' (Patient).

'Identified as a shielding patient – information continues to be supplied' (Patient).

'We received the information we needed, and they were extremely clear' (Carer).

'All of our queries or concerns about our family (cancer) member was dealt with immediately' (Carer).

'Reassured about my safety each time....I felt during my chemo I was never in any danger' (Patient).

4.13 There were those who felt that while they were listened to, and there was a high degree of attentiveness, this did not necessarily translate into having the questions that might be concerning them answered, or addressed in tangible ways that were helpful:

'I had a call from a nurse from my GP to ask how I was feeling but she wasn't able to answer my questions' (Patient).

'It has been difficult to know who to speak to. Even though our concerns may have been shared it is not sure how they have been taken forward and what will or has changed' (Carer).

4.14 The 53.66% (22) of respondents who said they did not feel that they had been listened too and that they did not feel that their concerns about COVID-19 had been heard said that they tried to find their own ways of addressing these concerns through internet searches and the media. There were others who said that contact between them and the relevant agencies had been very limited, and that this was aggravated by not actually knowing who to contact, and well as misinformation. There was moreover a feeling that the disproportionate risk of adverse impact in the case of Black people potentially contracting COVID-19 was not being taken seriously, as well as a lack of clarity about the advice being given to black and minority ethnic people. The following remarks are illustrative of this:

'Most of my information was learned from the internet or from the media' (Patient).

'Not sure who we as carers would be expected to contact, and the risk of African-Caribbean patients being taken to hospital didn't seem to be taken seriously enough' (Carer).

'I answered no because I was not concerned at the time. Received emails via What's App advising vitamin C and D could help however this was not relayed in any media information from the Government. However, checked the Welsh COVID advice recently and they do advise those of the ethnic minority group to take Vitamin D. What a surprise as I don't recall this being verbally announced' (Patient).

'I was able to refer to latest guidelines as they changed quite often but health professionals disinterested. Felt like we were not able to have a conversation and ask any questions' (Patient).

'Lots of misinformation given and no apologies or acknowledgement as to how it impacts on oneself. Misinformation recorded and being told by GP I need to fix it' (Patient).

4.15 **Has COVID-19 had an effect on your wellbeing as a patient or as a carer?** 78.05% (32) said that they did feel that COVID-19 had affected their wellbeing as a patient, or as a carer and 21.95% (9) stated that they did not feel that COVID-19 had affected their wellbeing as a patient or as a carer.

4.16 The respondents who said they did feel that COVID-19 had affected their wellbeing as a patient or as a carer replied that they felt they were living in a *'climate of fear'*, and that much of the fear they were experiencing came from concerns about themselves or their family members *'catching the virus'* and the resulting impact, including concerns about *'possible death'*. There were others who were left with feelings of *'guilt'* at being unable to shoulder what had previously been their share of the work burden, and those who experienced anxiety as a result of the seemingly contradictory nature of much of the information they received about *'who I can see and who I can't see'*.

'A lot of anxiety about potentially putting family at risk' (Carer).

'Anxiety about myself or loved ones catching the virus and having to be isolated. I have felt quite overwhelmed at times. I work at a school so having to work from home whilst my colleagues were struggling at school left me with feelings of guilt and anxiety. I am apprehensive about returning to work in September' (Patient).

'Concerned about the virus and if I would recover from it. Also feel like I'm under house arrest but am working from home and miss going out and interacting' (Patient).

'I have been indoors shielding for most part of the year. Roles are reversed in my household my husband is doing most of the things that I used to do. Anxiety in case the children bring it home' (Patient).

4.17 A recurring theme among those who struggled mentally with enforced isolation was the lack of social contact, feelings of guilt and anxiety because of the impact on themselves and loved ones, and efforts to ward off guilt and anxiety by engaging in diversionary activities around the home. In one instance that was cited, COVID-19 was actually passed on to a patient by the carer:

Our cancer patient (family member) struggles with isolation from family and friends' (Carer).

'As a single person self-isolation was sometimes hard to accept. Not going out but I did a lot around the home and garden' (Patient).

'Mental wellbeing for both myself and the cancer patient has plummeted' (Carer).

'I tested positive for Covid-19 and unfortunately this was passed to my Mum (cancer patient) and Dad' (Carer).

'Mentally this has been extremely exhausting. The anxiety levels are extremely high resulting in panic attack (Patient).

4.18 There were others who said that while there had been an impact on their wellbeing, the impact was a positive one in terms of the COVID-19 pandemic having caused them to reassess life, to recalibrate, and to focus on what they saw to be the things of real importance. This included becoming more physically active, and focusing on the positives in that, visits, albeit limited were still allowed, whilst acknowledging the need for a high degree of social isolation:

'I ensured that I increased my level of exercise and physical activity' (Carer).

'We have restricted all the visits at home from family members and friends to one visit per month' (Carer).

4.19 There were those who responded that the COVID-19 pandemic had not had a negative impact on their wellbeing and that they were able to pursue activities to fill the time during lock down as they were able to be outdoors. They also saw it as an opportunity to try new things and to enhance their wellbeing by controlling the things that they could:

'I occupied my time with lots of activities in the house and garden. I have an allotment and I spent a lot of time there' (Carer).

'The first week of lockdown was the hardest. I kept eating and eating and soon realise if I kept this up my health would be in a bad way. So, the second week everything changed. I started to follow exercise regimes online and started reading more. I also started a small kitchen garden which I enjoy. I decided in my mind that I can't control what's going on outside with the pandemic, but I can control what's going on in my home. So, during lockdown my mindset became more positive' (Patient).

4.20 Do you as a patient or the person that you care for have any other health conditions? 56.1% (23) said that they or the person that they care for did have other health conditions and 43.9% (18) stated that they or the person that they care for did not have any other health conditions.

4.21 The respondents who said they or the person that they care for did have other health conditions, referred to conditions such as bronchitis, arthritis, fibromyalgia, and hypertension, which some felt had become more severe as a result of lockdown and a lack of exercise. There were others who cited health conditions such as multiple sclerosis, asthma, low blood pressure, iron deficiency, anaemia, high cholesterol, osteoarthritis, hiatus hernia, migraine, hidradenitis suppurativa which is a painful long term skin condition that causes abscesses and scarring, diabetes, anaemia linked directly to fibroids which is most common in Black women, poor mental health including low mood directly related to the trauma of living with cancer, and concerns about being a cancer patient and/or carer in the midst of the COVID-19 pandemic.

'I have lupus and a mental health diagnosis and asthma' (Carer).

'In 2017 I was diagnosed with diabetes type 2 which is still diet controlled (Patient).

4.22 Were your other health conditions given consideration within your overall care and support during COVID-19 lockdown? 58.54% (24) said that their other health conditions or those of the person that they care for were given consideration within the overall care and support they were receiving during COVID-19 lockdown, and 41.46% (17) said that they were not.

4.23 The respondents who said that their other health conditions or the health conditions of the person that they care for were given consideration cited things such as *'extra inhalers for bronchitis'*, *'access to 'telephone consultations'*, *'reassurance'* about other health conditions, and availability of the GP to discuss any concerns. The following remarks enlarge on this:

'Due to my wife multiple myeloma, she was also screened for all the other types of diseases which could affect her condition' (Carer).

'I have my normal hormone injection, blood test and collection of my prescription' (Patient).

'GP was available for phone appointments for my concerns'(Carer).

'Yes. I was contacted and offered shingles and flu vaccines by my surgery' (Patient).

4.24 There were others however who cited a different experience, and who felt that there was less consideration given within their overall care and support which placed them in a position of feeling that they had to be self-reliant. The following remarks make this clear:

'My wellbeing has never been taken into consideration as I appear to have it all together. Didn't help at start of lockdown GP left for 3 months. So, I had no outlet. Then Covid

lockdown happened and I had more pressing things so had to rely on myself to get through' (Patient).

'Only urgent appointments considered due to lockdown, safety and time' (Carer).

'My health was never considered' (Carer).

4.25 Have you or the person that you care for missed any cancer treatments or had changes to your cancer treatment as a result of COVID-19? 43.95% (18) said that they or the person that they care for had not missed any cancer treatment or had changes to their cancer treatment as a result of COVID-19, and 56.1% (23) stated that they or the person they care for had missed cancer treatments or had changes to their treatment as a result of the COVID-19 pandemic.

4.26 The 43.95% (18) who said that they had not missed any cancer treatments and had not had any changes to their cancer treatment said that the continuity in their care had not changed. In addition, there were those who said that where appointments were not done in person, telephone and video consultations also ensured that continuity in care was maintained. This was explained in the following ways:

'All appointments and operations scheduled took place' (Patient).

'I'm in remission. Had blood test as usual and telephone consultation' (Patient).

'All appointments were never cancelled and what was not done face to face, it was either telephone or video conference calls' (Patient).

'Care continued' (Carer).

4.27 The respondents 56.1% (23) who said that they had missed cancer treatments, and that there had been changes to their cancer treatment, stated that their appointments were cancelled and placed on hold until further notice, that appointments and locations were changed around, and that they had to be persistent in their requests for appointments when symptoms became difficult for them to manage. The patients and carers who responded explained this in the following ways:

'Leukaemia treatments (for patient) were missed, and I was unable to get my bloods done (for lupus) and as a result was kept on a high level of steroids for an excess of 5 months' (Carer).

'Appointment was cancelled until further notice' (Patient).

'No treatment since January and missed continuous treatment sessions' (Patient).

'Appointments changed around-location, time' (Carer).

'Some appointments didn't happen as specified' Carer).

'MRI and other scanning appointments were put on hold' (Patient).

'Had to persist for further investigations when suffering from pain' (Patient).

4.28 There were others who stated that their treatments were stopped, and who experienced this as an additional burden that had been placed upon them, in addition to dealing with the potential impact of COVID-19, as well as others who felt that certain cancer treatment options were not actively considered because the country was in the midst of a pandemic:

'Focus was on palliative care whereas prior to COVID-19, there was discussion about treatments, but the pandemic prevented this, and I believe accelerated my father's decline and eventual passing' (Carer).

'My cancer treatment stopped for 3 months due to COVID. Had to deal with that as well as risk associated with COVID virus' (Patient).

4.29 **Are you concerned about leaving home?** 70.73% (29) said they were concerned about leaving home during the first easing of lockdown and subsequent targeted measures, and 29.27% (12) stated that they were not concerned about going out at the time of the initial COVID-19 lockdown easing and subsequent targeted measures.

4.30 The 70.73% (29) of respondents who said that they were concerned about leaving home said it was because despite the initial lifting of restrictions, they still felt vulnerable as the virus was *'still out there'*. There were those who were concerned because of having immune systems that were compromised and therefore a real fear was the impact on them of catching the virus, along with a concern that not everyone was following the guidance on cleanliness and social distancing. There were also concerns about the impact of a potential second wave:

'Restrictions may have lifted but my condition still makes me vulnerable as my neutrophil level has dropped since the beginning of lockdown. The virus is still out there. Not everyone is adhering to the safety guidelines. I am limiting my visits out in public' (Patient).

'Risk is still present and general public not fully grasped wearing masks etc. Feel safer in my house' (Patient).

'Concerned about the potential impact of a second wave on BME community' (Carer).

'Due to the potential of second wave the lack of government commitment to Black communities and those who are high risk' (Carer).

4.31 The concerns about going out extended to those cancer patients who said that while they were not in a group that had been advised to shield, they had nonetheless decided to shield. There were specific fears for black and minority ethnic people related to the disproportionate risk and impact, a fear of going out at all, a fear of going to certain places, as well as those who did go out despite their fears but took precautions when they did so. Carers too were concerned about

catching the virus and transmitting it to those that they were caring for. This was explained in the following ways:

'Have started chemo - immune system fragile. No need to expose myself to the virus that will be difficult to fight. Am working from home' (Patient).

'A slight concern about contacting COVID and passing it onto our family member with cancer' (Carer).

'The disease is still not eradicated so I wear a mask, and sanitize my hands as often as possible' (Patient).

'Although not in Shield Group, I think it is wise to observe the social distance, and protective protocols, given my illness and that the virus has not gone away' (Patient).

4.32 29.27% (12) said that they were not concerned about leaving home and this was because they were trying to put some normalcy back into their lives. There were others who said that while they did feel somewhat concerned, that they took protective measures as far as possible to mitigate the potential risk to themselves, to their families, and to others they made contact with. This was explained in a number of ways:

'There are so many different factors to this COVID situation, going out and wearing a mask or not is the least of it. I just do as I've always done traditionally' (Patient).

'Wanting life to return to normal' (Carer).

'Although cautious I do feel I do enough to protect myself and others' (Patient).

'Getting used to the new normal. Not being able to hug family members, being out in public places' (Patient).

4.33 **Did you have any particular financial difficulties as a result of the COVID-19 lockdown?** 31.71% (13) said that they had experienced financial difficulties as a result of the COVID-19 pandemic and 68.29% (28) said that they had not experienced any financial difficulty as a result of the COVID-19 pandemic.

4.34 The 31.71% (13) of respondents who said that they had experienced financial difficulties as a result of the COVID-19 pandemic said that this was because: they had no income as they did not qualify for the furlough scheme; because they worked on a contractual basis; because they did not qualify for statutory sick pay, or because their employment was insecure directly as a result of the worsening economic climate. There were those however who, despite being furloughed, still felt impacted by a sense of financial insecurity when looking at the longer term in respect of what might happen to them once the furlough scheme ends:

'Few commercial partners have gone out of business. Few commercial partners are reluctant to renew contracts before having a clear picture of a post COVID' (Carer).

'No income as not entitled to the furlough scheme' (Carer).

'I am still furloughed so don't know what will happen to my job' (Patient).

'I am on ESA and PIP and at times struggle to cover my outgoing bills as well as trying to cover other amenities such as gas, electric etc as am on prepayment meters' (Carer).

'Not being able to work and as I am bank staff, no access to statutory sick pay' (Carer).

4.35 The 68.29% (28) respondents who said that they had not experienced financial difficulties explained that this was because: their earning power had not been impacted because they were able to work from home; because they had been furloughed, or because they had enough money to meet their day to day living expenses and bills. This was explained as follows:

'I worked from home, so my salary was unaffected' (Patient).

'Am working from home' (Patient).

'Although it cost me more for shopping and getting around, I managed in caring for my brother' (Carer).

4.36 **Have you accessed any financial support services as a result of the COVID-19 pandemic?** 14.63% (6) said that they had accessed financial support services as a result of COVID-19 and 85.37% (35) stated that they had not accessed financial support services as a result of COVID-19.

4.37 The 14.63% (6) of respondents who said that they had accessed financial support services said that they had accessed the following support:

'Free school meals' (Patient).

'Universal credit. Furlough scheme' (Carer).

'Accessed support from CSUK' (Carer)

4.38 The 85.37% (35) who said that they had not accessed any financial support responded variously that they had no idea where or how to access support, or that they were not eligible:

'Not aware of any' (Carer).

'I do not know where to access help' (Carer).

'I am not eligible for a number of government support. I have accessed financial support with food from a local community group (Carer).'

4.39 During the COVID-19 pandemic, have you used any local weekly food delivery services for vulnerable people? 21.95% (9) said that they had used local weekly food delivery services for vulnerable people and 78.05% (32) stated that they had not used local weekly food delivery services.

4.40 The 78.05% (32) of respondents who said that they had not used local weekly food delivery services explained that this was because their earning power was not impacted given that they were able to work from home, because they were furloughed, or because they had enough money to meet their living expenses. The 21.95% (9) that had used local weekly food delivery services for vulnerable people received cooked meals from voluntary agencies, and used local foodbanks which met their needs. This was alongside other respondents who cited difficulties in getting deliveries, a lack of space to store food that was delivered, and a lack of nutritious food provided by food delivery services:

'Too hard to get deliveries and not enough space to do a large shop' (Patient).

'Met needs' (Carer).

'My local foodbank' (Carer).

'It met needs' (Patient).

'I did not qualify but in the last two weeks I have been in receipt of 2 cooked meals on a Friday from a local voluntary BME community centre' (Patient).

'Everything in a tin or dried. Better than nothing but not considered healthy' (Carer).

5. Case studies

5.1 There were five case studies, four patient case studies and one carer case study. They provide a vivid illustration of the experience of living with cancer or being a carer during the COVID-19 pandemic on a day-to-day basis, the impact in relation to the concerns about adverse outcomes and Black people, and the devastating impact when an adverse outcome, in this case, death, becomes a reality. The case studies also explore the impact of social distancing on community support networks, and cultural custom and practice, as well as some of the positives that people have either been able to take from the experience of lockdown, or that have emerged.

a) Gary Dean – Patient Case Study (African)

Gary was born in 1962 and is 57 years old. He is a self-employed Martial Arts Instructor, specialising in Wing Chun. Gary has a wife and son who lives at home. In April 2019, Gary noticed he had experienced a dramatic weight loss. He visited his GP who made an immediate hospital referral. Following an extensive series of examinations, over a six-month period, he was told there was a

nodule in his lung that required removal. In November 2019, a third of his lung was removed and a diagnosis of lung cancer made.

Since the operation, Gary has been unable to leave the house, mainly due to the recovery time from the operation, and subsequently, on strict instructions by the doctor to shield due to the COVID-19 pandemic. Gary feels that the impact of the operation, coupled with the effects of the lockdown, have affected his mental and physical health further. Added to this situation is Gary's profound sadness at not being able to attend his sister's funeral, who died of COVID-19. He also has major concerns regarding the financial impact as he is unable to work and provide for his family as he is the main breadwinner. As he explains:

'I was a very fit person and am a Martial Artist, but am not at this moment and the lockdown is exacerbating the situation. I was 100% before, now about 70%. I am self-employed and have to get back to work because my students will not hang around and I have to get some money to provide for the house but am not entitled to any, due to being self-employed. They said I didn't pay enough contributions. The NI stamp gets paid, but nothing else. My Mrs works 2 days per week and has had to increase her hours. Our son is unemployed. So, I feel like I have been left in limbo, cast aside. I was the head of the family, but I don't feel like I did before. I get tired easily....I was unable to go to my sister's funeral who died due to COVID-19'.

Gary talked about the isolation and anxiety he has experienced since his diagnosis and the additional fears since the outbreak of COVID-19, as he has still had to attend hospital check-up and specialist appointments. The sheer frustration at being confined to his home and garden is impacting his mental and physical recuperation. This Gary says has been compounded by the fact that most of the community services that provided him with much needed support, following his diagnosis, have been forced to close. Gary explained his feelings in this way:

'It's a headbanger. I can only sit in the garden for a certain length of time. I feel I am one of the forgotten ones. I feel like nobody really cares. They just leave me to my own devices and I've not spoken to anyone apart from Marcella from CanSurvive. In the beginning you had Macmillan's Centre coming to support and Marcella. They were great, but now they have closed everything down and the problem I have is there are things in my head, and I can't talk to my Mrs and I can't talk to my son and you can't go round to places'.

Gary talked at length about his ongoing vulnerability given that the virus is still in existence, and of the fear and confusion caused by the conflicting misinformation coming on a daily basis. Voicing further concerns that not all are complying with the requirement to wear appropriate shielding he explained:

'I've not spoken to my doctor since May. So, nothing at all. All they have done, is send me text messages about COVID and other information and no-one is telling me anything. The only thing I get is a text from the medical centre, saying don't forget to wash your hands, keep your distance from people and don't let people into the house and I don't know if they are saying this to frighten people. I am confused. COVID is on the telly all the time and it

worries me. I have anxiety and sometimes I stomp around the house through frustration and anger and stuff. Do you know what I mean? I am still on lockdown and loads of people are not wearing masks. That frightens me. The first time I went out to ASDA today, loads of people were not wearing masks and I wear two masks me. It's kind of like you have to have body armour on before you go out. If we are vulnerable, we should be given good advice and told what to do'.

In terms of the future, Gary feels he has no trust in the agencies he has dealt with to date, apart from Macmillan's and CanSurvive. He said he would refuse any further surgery or treatment because of how it has made him feel, and which he feels was not discussed properly with him. He is currently working towards getting his fitness level up so he can again practice and instruct as a Martial Artist.

b) Paula Edwards – Patient Case Study (Caribbean)

Paula Edwards was undergoing tests for a completely unrelated procedure when doctors found an abnormality. As a result, the procedure she was originally scheduled for was unable to go ahead. Paula explained that on reflection, she realised that she had been feeling tired and run down, and felt that she was possibly anaemic, but at the time, nothing had consciously registered with her as being particularly wrong. She was referred urgently to see a specialist, saw the consultant on 28 March 2012, and a diagnosis of kidney cancer was made. At the time of her diagnosis, Paula was also told that the cancer had spread, and that she had between 12 and 18 months to live. Understandably, Paula was extremely distressed at the time, and a major worry for her was her children. The eldest was daughter fourteen at the time and her youngest daughter was only four years old. The nurses were concerned about how Paula would drive home following the consultation because she was in pieces. As she explained:

'I said to the doctor, "run that by me again?" He was saying it to me, and it was like, no, no, no. I have heard him wrong, and I went to pieces. I was at the appointment on my own and I should have been warned in advance to bring someone. He just gave me the bombshell. But I got my head in gear and I drove home'.

That was over eight years ago and Paula is enjoying a full life. She has watched her children grow, and is surrounded by family and good friends, and although recently not at work because of the COVID-19 pandemic, she has been enjoying her work as a Community Care Officer with Nottingham City Council. Paula jokingly remarked:

'The doctors don't know how I am still here, but I put my trust in the doctors, higher powers with friends and family across the world praying for me. Emotionally I am very militant. Macmillan's helped me deal with the financial side, and I am so grateful for my social work background as I knew about DS 1500 which fast tracks you through the benefits system when you have been given a terminal diagnosis'.

Paula said of her experience that there are lots of things missing in terms of services for ethnically diverse populations, and that emotional needs are not being met in the case of Black people who

have been diagnosed with cancer. This stems from not getting appropriate services when it comes to wigs and hair treatment, and feel-good sessions for example, as they do not take account of the needs of Black people who have different skin colours and skin tones. Paula explained that it was this vacuum in support that had led to the creation of *Sistas Against Cancer*, of which Paula is a founding member. She put it in this way:

'MacMillan's, they do a brilliant job giving out grants and helping with the financial side which is really important. Sistas Against Cancer was set up because although there is other support out there, it does not always meet the needs of people of colour. The group does allow people of other ethnicities to attend and they do. I lost my colour due to the side-effects of the cancer medication and it had a big psychological impact as that is heavy stuff to deal with....I didn't look like me and this was confirmed by my four year old daughter saying "you don't look like my Mummy anymore". So, although we were set up for Black women, we do allow people who identify with us to come so there are people of other ethnicities'.

In relation to the COVID-19 pandemic, Paula said that she had felt very vulnerable on receiving the initial government letter about shielding, as the disproportionality became clear to her through the various news reports commenting on the high incidence of *'people of colour losing their lives'*. As the lockdown has eased, Paula has received a second government letter saying that she can now mix with another family member, and up to six people. However, Paula says that she still feels vulnerable while the virus is still out there and would rather keep herself safe and continue to shield as much as possible, and continue to isolate. In terms of the experience of shielding, Paula says she feels that she personally has been quite fortunate, and with *Sistas Against Cancer*, and the role that she has in providing more support.

In terms of the future, Paula faces it with hope, with optimism, and with realism, explaining that she has asked her consultant, whether she will see her youngest daughters' 18th birthday. To which she said the reply was that she has defied every expectation so far, so there is no reason why not.

c) Winston Carrington – Patient Case Study (Caribbean)

Winston is a retired man, age 70, who has three grown up children and two grandchildren. He was diagnosed with prostate cancer in 2016, had his procedure in 2017, and 12 weeks later, was given he all clear. He was not told to shield because at the time of the COVID-19 outbreak, his health as he says, was *'on the right side of good'*. The diagnosis he also says, forced him to undergo a complete lifestyle change:

'I changed my whole lifestyle, and I was already vegetarian, so I became a vegan. The only thing I have is a weakness for cheese but apart from that I have no animal products in my system, everything is plant based. I am in a really beautiful place at the moment, health-wise and life-wise, I love it. I am really happy with my life. The only thing I am missing is a companion'.

The lockdown Winston says has been the best of times for him as it has allowed him to take up new interests, to take a closer look at the way we live as a society, and to decide not only what he wants,

but what he doesn't want. He places a premium he says on health and not financial wealth and explained it in this way:

'The lockdown has done nothing to me. I'm retired and it has been the best time for me as it has allowed me to start my vegetable garden. It actually allowed me reevaluate my life in such a way that I know now that money is not everything because all the people who had that dough couldn't spend it when they were locked down. My health is more important. I sold my car a while back and I go on the train to Manchester and it's free because I am 70. If I want to go outside Manchester, then I pay from the outskirts and get a third knocked off. I have started doing Pilates now three times a week, and it has allowed me to think about my health more than I did before because I think I took it for granted and I am physically more fit now than before I had prostate cancer'.

About COVID-19, Winston says that he is not at all concerned as he has researched information from a variety of sources and believes he has all of the relevant facts that he needs. He says he follows the rules and wears a mask in places where it is a requirement, but that he does not restrict where he goes or being among people. As he explained:

'I did my research on COVID and for me it is the flu. There has been loads of COVID. So, for me it is about keeping my immune system healthy and I know that keeping my immune system healthy has got me through. I go everywhere so for me it's a case of being real, knowing that it's there and people who need to be shielded, I will shield them. I will put the mask on if people ask me to, but I don't walk around in a mask all day'.

In terms of the future, Winston is philosophical about the fact that life eventually comes to an end for all of us, and COVID does not really concern him in the least. He says that he is enjoying life and all that he has:

'I've got my three children who are all doing well in their careers. I also have two grandchildren, a boy of 4 and a girl of 9. I love being able to walk and the thing about it for me is that when I die, because we are all going to die, I want to die as healthy as possible. So, I think the way I look after my body will enable me to live another 20 years. In Barbados, now if you get to 100 years old, they put your face on the stamp so that's what I'm going for'.

d) Pauline Johnson – Patient Case Study (Caribbean, South America)

Pauline Johnson was diagnosed with multiple myeloma in 2009 at the age of 46. After having a series of illnesses and infections since at least 2007, Pauline was eventually admitted to hospital with a gall bladder infection which she subsequently had removed. After surgery, the doctors told Pauline that she had a very low blood count, and she was given a blood transfusion. Prior to her discharge from the hospital, she was told to make an appointment to see her GP. Pauline visited her GP who immediately referred her to a consultant haemato-oncologist, and she was given a bone marrow biopsy. The hospital called Pauline back to an appointment a week later and as she sat in the reception, she noticed whispers between the nurse and the reception staff and lots of comings

and goings. She was then called in to see the consultant and a nurse was there. That was when Pauline was told that she had multiple myeloma. Pauline says that the diagnosis did not immediately ring true added to which, she had never heard of multiple myeloma. In fact, Pauline recalls, that the consultant and the nurse were very surprised that she was not more upset. As Pauline explained:

'The consultant said that he wanted me to start on chemotherapy the next day and that was when it hit me. It never dawned on me that I had cancer. I never ever thought it was cancer. It never ever crossed my mind that it would be that'.

In relation to the COVID-19 lockdown, Pauline says that she has been advised to shield as she is on the list of vulnerable people. She says that while restrictions have lifted for others, for her that is not the case with the exception of hospital visits. A bonus she says is that she can speak more with her family and friends as many were and still are at home, and was allowed to work from home at the start of the lockdown, an arrangement that is now permanent. Pauline is also heartened by what she sees as a refocusing on social values. She explained this in the following way:

There is reading, listening to the radio, and the television so I was comfortable staying at home. I also am happy because I am working at home and am very busy with my job. I am managing the lockdown because people are at home and you can ring and talk to them. There has also been a realignment for the whole world and what they value, and people are realising that relationships and family are important. It's not ideal for everyone but I think we really needed it. Not in the way it has come about, but it has made everyone sit back and think. It's a new world order basically'.

Pauline says that she is quite happy being at home because she can find so many things to occupy her time, and that her experiences during previous rounds of treatment following her initial diagnosis means that she is accustomed to self-isolating. The whole situation with the virus Pauline says does cause her some anxiety when it comes to venturing out of the house now for hospital appointments but in the main for her Pauline says, the lockdown itself has been very easy to cope with:

'The social isolation I have coped with well. It doesn't bother me because I've done it before with my treatment the very first time after I was diagnosed, I had to self-isolate for a year before I could go back to work. The going out with COVID-19 has made me really paranoid. It was fine while I was at home and not going out at all but since I've been going back to the hospital, I've been wearing these masks and humongous sunglasses. You wouldn't recognise me if you pass me in the street. When I come back from the hospital I strip off at the door, I wash my face, gargle, get cotton buds with TCP and clean around my nose'.

When Pauline was initially diagnosed, she says that the prognosis was six months, because of the severity of the myeloma and the extraordinarily high levels of paraprotein in her body. That is now almost 11 years ago and Pauline, despite a relapse in 2019, is continuing to lead a full life. She has seen her daughter go through school and graduate from university, and is now focused on her career and her online start-up business in arts and crafts which is doing very well.

e) Lesburne Easie – Carer Case Study (Caribbean)

Lesburne Easie, or Les as he is known, is aged 60, and was diagnosed with prostate cancer in 2008. Since being diagnosed, Les has been doing very well and has been in remission for some years. A number of other members of his family were also diagnosed with prostate cancer at the same time as Les. The disease disproportionately affects black men, and at a younger age than is the case for the population generally. Les has two grown up children who are now in their 20's and who live in the family home with him.

Les explained that his wife, who had lupus but had been in remission for 10 years, and who had been shielding because of the pandemic, suddenly became ill with flu-like symptoms and a respiratory ailment. The symptoms worsened over the course of a few days to the point where his wife had difficulty breathing. Les called for an ambulance, the paramedics arrived, and after assessing his wife, said that they suspected COVID-19 and that she needed to be hospitalised immediately. His wife was taken to hospital that evening, the 11 March 2020, where the specialists at the Queen Elizabeth Hospital in Birmingham battled to control her breathing. On the morning of 12 March Les received a call from the hospital informing him that his wife's condition had become worse and that they had no alternative but to place her into an induced sleep. Les asked if he and the children could see her before she was put to sleep but was sadly informed that the procedure needed to take place immediately. Staff then spent some 11 days desperately battling to save her.

On Sunday 22 March, which was also Mothering Sunday, Les received a call from the hospital to say that his wife's condition had deteriorated, that her organs were shutting down, and that there was nothing else that they could do, and respectfully, asked to turn off the machine. Les asked if they could delay that process while he made his way to the hospital with his children and it was agreed. Les and his family spent a few moments with her in prayer and to say their good-byes. Elaine June Easie passed away moments later in the presence of her husband and children Jessica-Jade and Elliot Jordan. Les described the events leading up to it in this way:

'The events started over the weekend of 6th March 2020 when my wife began to cough and thought she may have been catching a cold from her daughter. By Monday 9th March June's coughing did not improve and she even spent time in bed throughout the Tuesday, but her condition was not improving. It got to the point where she couldn't breathe very well and I heard her coughing and it didn't sound right, so I called an ambulance.

When the ambulance guys arrived, they had masked up and they examined her. They said that her oxygen levels were quite low and that she needed to be admitted. They put the oxygen mask on her and took her to the hospital. I accompanied my wife in the ambulance and when we arrived, staff came out to meet us and placed masks on us. I asked what was going on and they said that they were taking precautions. After examining my wife for over an hour, I was informed that she had contracted double pneumonia and they suspected that she may have contracted COVID-19. Also, that she would have to stay in hospital until they could control her breathing.

The hospital called us at 5.00am the next morning to say that her body was shutting down and they had to put her into an induced sleep of which she spent some 11 days. We asked if

we could see her before she was induced but they said there was no time and they needed to act now. June spent some 11 days in this sleep state critically ill. On 21 March we received a call from the hospital informing us that the consultant wished to speak with us in person. They said her organs were riddled with COVID and that they had to no alternative but to professionally request that the life support system be turned off very soon and maybe within 24 hours. The doctors said that if she were to survive, she would not have any quality of life, so the recommendation was again, to turn the machine off. On Sunday 22 March Elaine June Easie was released from this life to be with her Jesus in the presence of myself and our precious children’.

Les explained that this period during lockdown has been particularly difficult at times and that the COVID-19 pandemic had to be the worst time ever because people have not been able to get closure through the normal rituals within the Caribbean and church communities surrounding death. This includes the active support of immediate and extended family, and the wider community which helps you to get through it. The period following his wife’s death had been a time of bonding with his son and daughter, and together, they are trying to come to terms with the sudden passing of June. For others who also knew and cared for his wife, they have not been able to get any form of closure. As he said:

‘It is never a good time to die but this has to be the worst time ever for losing a loved one and for us being Caribbean people when everyone comes around and provides that support and you get through it together. However, being on lockdown provided an opportunity for us as a family to bond even closer together as we began the process of life without wife and mother. Having to bury our beloved June without a proper Christian Pentecostal church service coupled with the fact that only 6 persons could attend the internment, robbed us even more and has made closure even more difficult because we couldn’t give her the send-off she duly deserved. The undertaker said that they were notified by the hospital that when they were to collect the body, it would be placed in a body bag of which it is not to be tampered with and should be placed immediately into the coffin, and you cannot touch or dress her. For those who were close to June, there was no body to see and no church service to attend to even see or touch the casket to make it tangible and help bring closure. It is still not real for the many who knew her well and are still ringing to say they cannot believe she is gone’.

There are happy memories that Les draws on and this includes a memory from when they got married as young people, many years ago when his wife asked him if there was any place he wanted to go to or any particular thing that he wanted to do most of all. He replied that he would love to go to afternoon tea at the London Ritz. All these years later, in February of this year, a month before she became ill and died, his wife took him for afternoon tea. As Les says:

‘Going together for afternoon tea. That is the first thing she asked me and the last thing that she did for me. I will cherish that memory for the rest of my life’.

6. Conclusion and recommendations

6.1 This is a small-scale study to begin to understand some of the experiences of the COVID-19 pandemic within the Black community. While it is not possible to make definitive statements with a high degree of confidence, there are some themes that can be drawn out. In relation to information and support, there were those we felt that they were given the right kind of information and support, and whose experiences of treatment remain unchanged, and which they remained confident in, as well as those who said that they experienced access to treatment, care, services and support as being compromised during the initial lockdown. It was the case that alongside official advice which also constantly changed, there was a wealth of information emanating from a variety of sources, including social media on COVID-19, some of it contradictory. This therefore provided a fertile space in which misinformation could grow, thus adding to the existing fears of patients and carers, many of whom were already prone to anxiety because of what they were dealing with.

6.2 There were patients and carers who felt that their wellbeing was severely impacted by the COVID-19 pandemic. This centred principally on fears of what could potentially happen, concerns about the impact on Black people in particular given their higher risk burden, as well as the impact of isolation on mental health. Indeed, one of the case studies shows the devastating impact of a death from COVID-19 on family members, the impact of the restrictions on the grieving process, and on networks of support and cultural practices that would formerly have helped people through. At the same time, there were those who experienced the lockdown as a time of personal growth, and as providing the opportunity to do things differently and to reassess the way they lived their lives. It also provided some the opportunity to work differently and where employers were able to take advantage of the furlough scheme, any potential financial impact was cushioned. At the same time, there were those who were financially impacted and tried to mitigate this by using food delivery or other community services, as well as others who experienced the impact but had no idea where to go for help and support.

6.3 Now that a COVID-19 vaccine has been developed and approved, it is important that there is a clear understanding of attitudes of all people towards the vaccine to guard against the risk of oversimplification, vis-à-vis that black people are more prone to being distrustful of it. There also needs to be a discussion about clinical research more generally since there is evidence that views within black and minority ethnic communities towards clinical research are positive as well as negative but that the latter, for some, may be formed by factually based historic concerns that are not openly discussed or acknowledged, and may mesh with contemporary concerns. At the same time, there also needs to be a focus on those actually engaged in clinical research and developing research protocols in terms of their selection processes, their awareness of ethnicity as a social construct, their views on the importance of inclusion, and how their own experiences may impact inclusion.

Recommendation

6.4 It is recommended that:

1. More intensive and extensive research with black and minority ethnic communities to understand diverse experiences during the of the COVID-19 pandemic, this should include

targeted work with patients and carers in the older age groups, and younger patients and carers.

2. Further research be undertaken to capture the views of those who are digitally excluded and may not have access or unlimited access to computers or mobile devices.
3. More intensive and extensive research is undertaken to explore the views and attitudes of black and minority ethnic communities, and the views of healthcare professionals to the COVID-19 vaccine.
4. The report be shared with the organisations that have supported this project.

Appendix – Sources

1. Beyond the data: Understanding the impact of COVID-19 on BAME groups, Public Health England, June 2020.
2. The NHS Long Term Plan, NHS England, January 2019.
3. National Cancer Experience Survey, 2018.
4. Skyers, Sophia, Kerr, Campbell, Johnson, Pauline, Count Me In! A qualitative inquiry into the views of black Caribbean and black African communities on clinical trials, clinical trial enrolment, and clinical research, The Basil Skyers Myeloma Foundation, 2017.
5. Listen Up! Multiple Myeloma in Black Communities: An Unequal Risk Burden, The Basil Skyers Myeloma Foundation, 2015.
6. BME Cancer Patient Information Survey, BME Vice, 2012: The uncomfortable reality of prostate cancer in black African-Caribbean men, BME Cancer Communities, January 2013.
7. Hear Me Now One Year On: Communities' call to action to address prostate the burden of prostate cancer in black African-Caribbean and black-African men, April 2014.
8. David Olusoga , Black and British: A Forgotten History, Pan Books, 2016.
9. Bamba C, et al. J Epidemiology Community Health 2020;0:1–5. doi:10.1136/jech-2020-214401.
10. Intensive Care National Audit and Research Centre Report on COVID-19 in critical care 17 April 2020.
11. Bailey, Suzie and West, Michael, Ethnic Minority deaths and Covid-19: What are we to do? Kings Fund 30 April 2020.
12. Covid-19 the impacts of the pandemic on inequality, Institute for Fiscal Studies, 11 June 2020.
13. Platt, Lucinda, and Warwick, Ross, Are some ethnic groups more vulnerable to COVID-19 than others? Inequality, the IFS Deaton Review, May 2020.
14. Beyond the data: Understanding the impact of COVID-19 on BAME groups, Public Health England, June 2020.
15. BME Cancer Patient Information Survey, BME Cancer Voice, 2012.
16. National Cancer Experience Survey, 2018.

©BME Cancer Communities 2021

BME Cancer Communities

Foxhall Lodge | Foxhal Road | Nottingham | NG7 6LH
www.bmecancer.com

CIBS IQ Research

Email: sophia@skyers-morris.co.uk
Mobile: 07956 572983 | Phone: 0208 311 7742