

Written evidence submitted by Judith Neptial (CSV0064)

Dear Mr. Hunt

I would like to thank you for your kind words, for truly listening to me as I expressed my experience, and for prompting others to focus on the salient points I raised. This allowed me to feel that I made a meaningful contribution to the committees' discussion and to not feel invisible in the time that I have left. To have someone like yourself and the committee champion my points is something that I will remember for the rest of my life, and words will never do justice. In one morning, you managed to take away some of the indignities that I have suffered over the last three years. This experience has demonstrated that people such as yourself, do truly care and are actively trying to address the issues that black people face, as a community. I believe if others practice the kindness you demonstrated that it will help to rebuild the lack of trust that prevails within my community. As requested, I have listed points that would benefit people living with cancer as well as some of the shortcomings which I feel are specific to my community.

1. The non-communication between healthcare professionals, which led to no accountability being taken for the direction or implementation of my care plan and I believe many others.
2. The lack of cultural competence education, for health care providers, especially in health awareness of the specific needs of different ethnic groups. There are key and fundamental nuances between ethnicities, such as deference in the case of the Afro-Caribbean community. Simply put, ethnicities have unique social and racial biases that need to be seen, acknowledged, and addressed. All minorities do not have the same likes and dislikes.
3. Comprehensive, good-quality data is essential to enable health care providers to identify the specific needs of different ethnic groups, so that they can respond with tailored strategies and policies to address any inequalities, and to track the impact of these strategies
4. Poor awareness of risk factors of cancer symptoms, and socio-cultural and practical barriers, i.e communication contribute to lower cancer screening. This consequently impacts at which stage the cancer is diagnosed which directly affects the impact of treatment outcomes and ultimately mortality.
5. The assumption and expectation that cancer patients will have the time and the ability to understand, be able to effectively research options available to them as well as to navigate the NHS policies and procedures. Which even NHS employees often seem unable to navigate.
6. The lack of transparency in relation to treatment option disparities between boroughs and trusts highlights what I can only deduce as the reluctance of hospitals and senior medical staff to refer/discuss alternative options with patients, even if they are not specialists in that chosen field.
7. A lack of knowledge pertaining to hospitals' specialisms. A total lack of accountability in relation to funding initiatives for different cancers. It should not be that because I am black

woman and have a stomach cancer that my chances are significantly lower than a white woman who is diagnosed with breast cancer. I totally accept given the demographic of the country that my survival rates will be less but not so significantly.

8. A consistent person to advocate for the needs of the patient that is independent of the hospital.
9. The impact of Covid has led to an overall higher mortality rate in black cancer patients, this is due to the disparities in socio-economic living conditions, which has always impacted health care inequalities, as well highlight the cancer healthcare postcode lottery phenomenon.
10. Creating a care plan which is not collaborative. Meaning, if the general route of chemotherapy is not agreed accepted or agreed upon with the patient, then patients can be left in an 'orphanless', situation with no health care provider willing to take on their care. Unfortunately, I have experience of the same.
11. Cancer patients are only screened for the area where the primary cause of cancer is initially found. This leads to many cancer patients being unable to protect themselves sufficiently through access to screening services for other parts of their body, as when cancer resurfaces, it is nearly always in another part of the body - this was my experience. At least 3 women in my 'From MeTo You' group shared the same experiences; they were told that they were cancer free and consequently denied further screening. Only for them to lose their battle with the disease when the cancer resurfaced aggressively in other parts of their body. If their concerns had been listened to, or been made aware of the possibility of this happening, then they may have been alive today. Simply put - they did not feel that they could or should challenge the opinions of the medical profession. This imbalance of power and privilege, I believe was a contributing factor to management of their illness and ultimately, their deaths.
12. The process for obtaining a second opinion is extremely difficult for a patient to navigate and their care team are always informed which should not be the case. As cancer patients are extremely vulnerable and should not have the added burden of having to explain to their care team why they feel they need an alternative opinion. Compounding this fact is that, the more senior the medical professional is, the less likely they are to be open to being challenged.
13. There is a complete lack of trust between ethnic minorities and the NHS who need to work far more effectively with grass roots organisations such as **'From Me To You'**, to bridge this gap and provide a comprehensive break down of the needs of those communities. We need organisations that are consistent and do not disappear due to a lack of funding, there need to be provisions for these organisations to act independently so they can give a true and honest account of the needs of their communities, without having to worry about funding initiatives.
14. Cancer patients often are treated the same as people who do not work/ 'work shy'. But cancer is not a choice and should not be judged in this way.

15. Trial drugs are currently available to cancer patients, however regardless of whether a trial is working effectively or not, the pharmaceutical company has the option to end the trial once they have amassed all of the information that they require. Vulnerable cancer patients place their lives in the hands of these organisations but crucially, the patient is not sufficiently protected, even if a treatment works effectively, as the pharmaceutical company upon the collation of their test data, are under no obligation or duty of care to continue to facilitate the drug treatment. The patients, who I may add, have contributed so selflessly to these specific trials, even in the knowledge that the drug will more than likely go on to be used for wider use at a later stage. Those patients who have contributed so much, are left to die as they are now surplus to requirement once the trial drugs have been withdrawn. In my humble opinion, that is not humane or fair in a country that prides itself in its ability to do the right thing.

Macmillian have been a consistent form of support and have provided insurmountable assistance to our organisation: 'From Me To You' in supporting us in creating greater awareness as well as providing the group with an initial grant to begin, when no one would listen. However, in order to be a consistent voice for my community, as well helping to bridge the gap between ethnic minorities and health care professionals, we need to organisationally transition from more than a simple pilot programme unable to fulfil the long-term needs of a community feeling left behind, to one of an organisation that provides a permanent voice, pertinent and dedicated research to the long term wellbeing of black cancer sufferers and the wide learnings that can come from our existence .

Feeding a community for a day is not the way forward. We should empower the community with the support and tools to feed themselves for a lifetime. We implore you to help us to feed ourselves and to not "Mind the Gap" as Peggy Pakosta's incredible research shows but to bridge the gap.

Once again I humbly thank you for listening.

Best wishes

Judith

Feb 2022