IN THE MATTER OF THE UK COVID-19 PUBLIC INQUIRY BEFORE BARONESS HALLETT

MODULE 4: OPENING STATEMENT OF THE FEDERATION OF ETHNIC MINORITY HEALTHCARE ORGANISATIONS ("FEMHO")

A. INTRODUCTION

- 1. These written submissions are provided on behalf of FEMHO in advance of Module 4 opening on 14 January 2025. We thank Your Ladyship for the opportunity to present on behalf of FEMHO and consider it is of critical import to consider the gravity of issues and broader context which informs FEMHO's substantial interest in Module 4. This Module provides a crucial opportunity to scrutinise how vaccine development, policies, strategies, and rollouts accounted for or failed to address these disparities. Our submissions focus on structural inequalities, institutional shortcomings, and opportunities for systemic reform.
- 2. Module 4 seeks to examine important matters in the sphere of Vaccines and Therapeutics. As a consortium of Black, Asian and Minority Ethnic health and social care workers ('HCWs'), FEMHO's interests in this area of investigation are driven by concerns about whether structural inequalities, including scant regard for the public sector equality duty ("PSED") and equality impact assessment ("EIA") influenced the development, efficacy and rollout programme of vaccines and therapeutics to Black, Asian and Minority Ethnic HCWs and communities.
- 3. FEMHO provides the Inquiry with a uniquely informative voice, given the unequal impact of the pandemic on Black, Asian and Ethnic Minority HCWs, and is uniquely well placed to assist the inquiry through the dual prism of inequalities faced by their communities and in their role as HCWs. We will be traversing a diverse range of testimonies from Bereaved Families Groups, Vaccine Injured Groups, vaccine manufacturers, former Government ministers and representatives and vaccine experts. The expert evidence from frontline medical professionals, such as FEMHO members illuminate this disproportionate impact and speak directly to the comprehensive List of Issues in this module. They will do so by bringing the benefit of their professional expertise and personal lived experience of the impact of the pandemic at all levels

within the health care systems across the UK, and also from the perspective of the communities where the disparity in the devastating and direct health outcomes are a well-trodden and firmly established path.¹ FEMHO look forward to actively participating in this important module.

4. FEMHO believes there is an urgent need to address the systemic inequalities and institutional barriers that have contributed to the disparate impact of the pandemic on Black, Asian and Minority Ethnic communities. We are committed to advocating for policy reforms in the areas exposed and shown to be lacking in Modules 1 – 3, and in the areas that will be highlighted in Module 4 (and thereafter), including supporting initiatives aimed at promoting equality, diversity and inclusion within healthcare. By actively participating in this module, FEMHO seeks not only to provide insights into past shortcomings but to assist the Inquiry by contributing constructively to the development of recommendations for solutions that will safeguard the health and well-being of all individuals, regardless of ethnicity or background, going forward.

B. SCOPE

- 5. FEMHO acknowledges that the overriding focus will be on the: "systems, processes and outcomes; how they can be improved; on preparedness and the core decision-making; and on the general impact of those decisions. As part of that analysis, Module 4 will consider how pre-existing inequalities impacted particular groups." FEMHO particularly welcomes that the Inquiry will expressly address the impact of all decisions in respect of the vaccination rollout, on marginalised groups and communities. This distinct focus provides a vital lens through which to understand and address the intersection of health inequities and public health policy.
- 6. A thread running through and at the heart of these issues is the question of trust. Trust is pivotal in overall public health efforts and is essential if a successful voluntary vaccination programme is to be a success. The question of trust is particularly poignant for ethnic minority communities, in which there exists statistically lower levels of trust in government and public bodies. The underlying reasons are myriad and have been well-documented, but unfortunately not well addressed, for years. Culturally sensitive and effective communications, engagement,

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¹ This Inquiry has helpfully illuminated and contextualised the clear link between health inequality within the healthcare system. Professor Clare Bambra, in addressing the question posed in the course of her evidence in Module 1 of what the impact of racism and inequality is, stated: "People from minority ethnic groups are much more likely to be living in deprivation, so everything that Professor Marmot outlined in terms of the health impacts of poverty, housing and so on applies kind of even more so, it's amplified for people from minority ethnic groups. So, for example, 50% of Bangladeshi and Pakistani households are in the 20% most deprived neighbourhoods, compared to 17% of the white population." [16 June 2023, p.18 lines 14-22]

consultation and transparency are all vital components to gaining trust. Unfortunately, these were areas in which we consider there to have been repeated failures and missed opportunities. Often decision-making compounded, rather than mitigated, issues of distrust in our communities.

- 7. FEMHO welcomes the inclusion of Vaccination as a Condition of Deployment ("VCOD") in its scope and particularly urges the Inquiry to consider and explore the impact of the policy on equality and confidence. In his Module 4 Witness Statement, Dr Salman Waqar explains that the advancement of the VCOD scheme was a significant stressor and key issue for FEMHO members and only added to the climate of fear and coercion that existed during the relevant period. The policy came at a time when HCWs were already overstretched and overburdened, and those from minority ethnic communities were feeling and experiencing starkly disparate impacts.
- 8. HCWs felt there was little guidance or sensitive communication over the VCOD mandate, nor any time or space afforded to consider the consequences of it. Dr Waqar describes how those FEHMO members who felt able to voice concerns with their seniors reported they were mostly met with hostility, passivity and/or silence, which in turn compounded the distrust they felt.
- 9. Even though the policy was ultimately abandoned in the health sector, the damage was for the most part already done. Dismissal letters had, we have heard from members, already been drafted. Relationships and trust were already damaged, in some cases beyond repair. Many had already taken steps to get vaccinated prior to the U-turn despite having grave concerns about doing so, feeling they had no choice for fear of losing their jobs. Others who did not choose to get vaccinated continued to feel stigmatised by their managers and colleagues even though there was no mandate. FEMHO consider this to be an area the Inquiry must examine thoroughly, including regarding the consultation process in Government, the practical, legal and ethical implications of the policy, the competing interests at play and the impacts the policy had on different sub-groups.
- 10. Similarly, FEMHO also welcomes the Inquiry's consideration of the Government's communications regarding vaccine passports across the four nations and the impacts that this had on equality and confidence in the vaccine process.

- 11. Regarding the barriers to vaccine uptake, FEMHO are pleased that the lack of confidence that ethnic minority groups expressed in the Covid-19 vaccine will be examined as well as the action taken to address and improve confidence, including examination of misinformation. We remain steadfastly committed to ensuring that the terminology used reflects the sensitivities and complexity of the issues at play regarding confidence in vaccine use.
- 12. On this subject we note that as well as "hesitancy" language, the "hard to reach" mantra is disappointingly once again peppered through the evidence disclosed thus far. In Module 3, FEMHO member Professor J S Bamrah (amongst others) gave evidence explaining why it is that this terminology is particularly unhelpful, noting: "it sends the wrong signal because it implies that "The problem is with you and not with us"." We submit that this unhelpful phraseology ought to be abandoned entirely, and that in future more effort should be invested in understanding their needs and concerns, and establishing culturally sensitive ways of engaging effectively with these communities so they are not forgotten or routinely dismissed as unreachable. Certainly it should not be given any credence as an excuse for inaction.
- 13. FEMHO is concerned about the influence of structural racism and disparities in vaccine trials and its influence on UK Covid-19 vaccine uptake. Ensuring future vaccine trials are more inclusive, i.e. by having proportions of participants that are reflective of their representation in the overall population, and rebuilding trust among underrepresented groups, are critical areas for investigation. Hand in hand with this must be a concerted and ongoing effort towards devising strategies (in consultation with local communities as well as expert stakeholders) for increasing confidence among ethnic minorities in vaccine research and clinical trials to ensure that vaccines and therapeutics are being adequately tested in diverse populations.
- 14. In this regard, FEMHO implore the Inquiry to consider reforms which can ensure pharmaceutical companies that repeatedly fail to improve on clinical trial diversity are held to account. Such data should be published and made accessible to the public. As we have seen throughout the relevant period, it is not just enough to identify issues and offer criticism, this must always be accompanied by real blueprints that can be enforced to ensure there is long-lasting and sustainable change.

 $^{^2}$ Module 3 Transcript Day 17, 8 October 2024, 50 / 22 - 51 / 16

- 15. What has become clear from reviewing the expert evidence so far in this module, is just how stark the statistics are regarding the levels of engagement and inclusion of ethnic minorities in the requisite vaccine trials. Dr Prieto-Alhambra, in his report on vaccine safety, confirms that over 90% of the participants in the UK-based AstraZeneca vaccine trials were White. For the Pfizer vaccine Phase III trial (Polack et al., 2020), almost 83% of participants were White and the figure is almost 80% for the same in the Moderna Phase III trials. The evidence is clear that ethnic minority groups were vastly underrepresented, and the resulting impact of this on understanding risk-benefits must not only be recognised, but thoroughly scrutinised.
- 16. In addition to the issues associated with clinical trials, we remain concerned by the longstanding lack of investment in research and development generally of therapeutics specifically designed and appropriately tested to ensure they meet the unique physiological characteristics and health conditions prevalent among minority ethnic populations, perpetuating health disparities. Similarly limited are the existence of ethnicity tailored treatment plans, despite it being recognised that pathophysiology differs. Given what we know about wider issues of racial bias in the healthcare sector, for example the issues with oximeters, this is an issue requiring urgent attention.
- 17. FEMHO seeks investment in a programme to combine expert and lay guidance as to an effective framework for engaging and learning from underserved and marginalised communities in consultations to address the root causes of vaccine disparities, including guidance on what kinds of consultation methods have been shown to work best with underserved ethnic minority groups, and what factors should be prioritised in such consultations to ensure their success. Such frameworks will go some way to rebuilding trust in vaccination processes within a healthcare system that has been found to consistently fail such communities.
- 18. FEMHO is encouraged that issues regarding public messaging and outreach will also be explored in this module. FEMHO has been clear that much of the misinformation that ensued during the relevant period was caused by poor public messaging, and lax communication. We have been disappointed to read of the decisions made at government level not to address the spread of disinformation, the absence of which hindered the efforts of FEMHO members when they went out into their communities to try and encourage vaccine uptake and dispel circulating rumours.
- 19. The inadequacies in the accessibility and cultural competence of public messaging and communications is another pre-existing issue that has persisted unaddressed for many years and

which the Government failed to adequately prepare for or address during the pandemic. In light of the concerning delays in Government action to address communication issues, and the spread of disinformation, FEMHO members' staff networks and organisations such as BAPIO, BIMA, Black Women in Health, CamDocUK, Sudan Doctors Union, Medical Association of Nigerians Across Great Britain and MDC among others took up the baton once more in effort to fill the gap and ensure that ethnically diverse communities were reached and properly informed.

20. As Dr Salman notes at paragraph 49 of his Module 4 Witness Statement

"At a minimum, the government should have ensured that public messaging was made accessible in languages to meet the needs of local and national communities. We could and should have enjoyed academic linguistic support to help with this effort and enrich the translations of infection control information many of our members were trying autonomously to disseminate among their communities."

- 21. The Community Champions scheme is touted by some witnesses as an overwhelming success. However, our members have reported serious concerns about the efficacy of the scheme. Some were not even aware of its existence which, given we were amongst the target audience is very concerning. Particularly given the vital role and efforts of our members at the time to engage with their communities and do similar outreach work, many were disappointed and perplexed by how the champions were selected and why so much investment went to this one scheme as oppose to supporting grass root organisations and networks already doing valuable work on the ground as trusted members of their communities. For these reasons we urge the Inquiry to consider the evidence as to the success of the scheme critically.
- 22. Whilst not expressly covered in the List of Issues, the Yellow Card system has been covered by experts to the Inquiry and is embedded as relevant to the safety and surveillance of the Covid-19 vaccines, in particular as to how information related to risk and how adverse effects were conveyed to the public. FEMHO maintain our view that the scheme is fundamentally flawed and is in need of urgent reform.
- 23. The MHRA have touted that the Yellow Card reporting system collects information such as ethnicity and other key characteristics to produce safety signals for certain groups, and that the Yellow Card portal developed during the pandemic was rigorously tested before rollout. However, the system has been criticised for limited outreach to ethnic minority communities and insufficient multilingual support. Were the tests carried out inclusive of culturally diverse

populations? Did they account for barriers such as language proficiency, digital literacy, and cultural nuances in reporting adverse events? What specific steps, if any, were taken to ensure that ethnic minorities were adequately informed about and encouraged to use the Yellow Card system during the pandemic? FEMHO raise these questions because our experience is that public knowledge of the Yellow Card programme in our communities is and was limited and narrow, as is access to it. The reporting system has until very recently only operated in English and it is located in a certain part of an online website which is not easy to navigate to. Whilst some guidance leaflets have now been translated this came at a very late stage and we do not consider it goes far enough; altogether it is and was not an accessible system, and this discourages reporting. The result of this is a potentially very significant missed opportunity to capture potential safety issues arising in many population groups.

- 24. Ensuring cultural competence in the design of public health tools, particularly tools that are there to collect data so that impacts can be assessed accurately, can enhance the reach and effectiveness of public health programs. FEMHO have questions in relation to MHRA's strategy (or lack thereof) in engaging with marginalised communities and seek to know more as to whether these considerations were part of the MHRA's development process for the Yellow Card portal. We are keen to work with them on solutions to improve the system and its reach.
- 25. Additionally, FEMHO is encouraged that mis/disinformation and the UK Vaccine Damage Payment Scheme are included in the planned scope as these were further matters FEMHO has made submissions on previously. We are keen to explore what if any consideration and/or steps were taken by government (in particular the JCVI) to address these issues and also whether those dealing with the vaccine manufacturers explored any action they could take (including market shaping strategies and/or regulatory requirements) to put in place equality audits and enforceable safeguarding measures, to increase confidence and address the discrepancy in uptake amongst minority ethnic communities.
- 26. We are particularly keen that careful consideration be given to the lessons that may be learned and recommendations which may be identified regarding reducing inequality issues associated with vaccines and therapeutics in preparedness for any future pandemic. FEMHO seeks to expand on this substantive issue and is keen that these vitally important matters be explored with witnesses including experts during their oral evidence to obtain a range of insights into how inequalities may be better tackled and ameliorated in the future.

- 27. We reiterate the key importance of the Inquiry's stated resolute commitment to placing "possible inequalities" at the "forefront" of its investigation, which must involve an unflinching and thorough exploration of whether institutional and structural racism and inequality played a part in the development, procurement and use of Covid-19 therapeutics and vaccines (including the implementation of the vaccine rollout programme) and, if it did, the resulting impact on those vulnerable groups in the healthcare system across the UK. This exploration is crucial because the effects of such racism and inequality, if found to have occurred, would have had a profound impact on vulnerable groups within the healthcare system across the UK.
- 28. We reiterate that it will be essential that Module 4 fully examines through a lens sensitive to inequalities some of the key issues in this area including:
 - a. The development, trialling and procurement of Covid-19 vaccines and the implementation of the vaccine rollout programme (and whether the public sector equality duty (PSED) was adhered to in these processes.
 - b. The treatment of Covid-19 through both existing and new medications; and how equitable access to such treatments was ensured.
 - c. Unequal vaccine uptake including the use of pre-existing knowledge in the identification of, and any pre-emptive and mitigating action taken in respect of, groups which were the subject of unequal uptake.
 - d. Equitable representation, diversity and consideration of vulnerabilities and needs and mitigating measures to protect minority ethnic communities in decision-making regarding vaccines and treatments, in light of pre-existing known risk factors.
 - e. The multi-factorial issues around vaccine confidence in Black, Asian and minority ethnic HCW's and wider communities, and the role which thematic lack of data on ethnicity played.⁴
 - f. The role played by government communication and messaging and the decisions taken by the vaccine taskforce (including consideration of the impact of the diversity of its make-up on such decisions), which is likely to be a key underlying factor as individuals needed to be in a position to make a fully informed choice about the vaccine. By way of example, some of our Muslim members were worried the vaccine might include non-permissible ingredients, as other vaccines have in the past.

³ See BMA analysis of the CRED (Commission on Race and Ethnic Disparities) published its Race report on 31 March 2021.

⁴ https://www.newscientist.com/article/2266017-nhs-england-criticised-over-missing-ethnicity-data-for-covid-19-jabs/

- g. The role of accessibility in terms of language, in that within groups where English was not their first language, they were less likely to have been vaccinated or received a booster⁵.
- h. The absence of clear and accessible official information which led to misinformation spreading via press and social media with many left not knowing what or who to believe.
- i. Culturally sensitive communications strategies, including language, community outreach and transparency around the yellow card scheme.
- j. How vaccine access for vulnerable ethnic minority groups—particularly in deprived areas—could have been better managed during the COVID-19 pandemic?
- k. Culturally competent vaccine confidence training has been referred to by experts and we seek specific examples of successful frameworks or models (either within the UK or internationally) where such training has been effectively integrated into public health strategies.
- 1. Effective steps that could be taken to target the demographic related to older populations from Black, Asian and other ethnic minority groups; including whether a community-driven health model (e.g., using trusted community leaders or health ambassadors) would have resulted in earlier or more effective outreach.
- m. Specific changes to the JCVI prioritisation framework for future pandemics to ensure that risk factors such as ethnicity and deprivation are factored into early access to vaccines.
- n. A long-term action plan for integrating cultural competency training at all levels of the healthcare system, from front-line workers to policymakers, to ensure more equitable pandemic responses.
- o. How the UK government may institutionalise culturally competent practices so that they are not just reactive during pandemics but part of ongoing healthcare delivery.
- p. How future pandemic preparedness plans may embed ongoing health monitoring for vaccinated individuals from underserved or ethnic minority groups in a proactive rather than reactive manner.
- q. How workplace policies for healthcare workers, including vaccine mandates, supported or undermined vaccine confidence among ethnic minority staff. Did

⁵ Health Foundation, "<u>The Continuing Impact of Covid-19 on Health and Inequalities</u>," David Finch and Adam Tinson, 24 August 2022.

- employers implement culturally competent communication and support frameworks tailored to their diverse workforce?
- r. Explore whether access to booster vaccines was equitable for minority ethnic groups and if barriers persisted over time. Additionally, assess whether these groups received equitable follow-up care or monitoring for vaccine-related side effects.
- s. Evaluate the extent to which the government effectively engaged with faith and cultural leaders to address specific community concerns, such as religious permissibility, and to amplify vaccine messaging within trusted networks.
- t. Assess the effectiveness of training provided to frontline vaccination staff on engaging with diverse communities. Did these trainings address unconscious bias and foster trust-building with less confident or underserved populations?
- u. Investigate whether the government leveraged its procurement and investment power to influence global vaccine manufacturers to prioritise diversity in clinical trials. What strategies could be implemented to ensure vaccines are developed with diverse populations in mind?
- 29. Given the gravity of the situation and the potential implications for public health and societal trust, it is essential that the Inquiry does not shy away from investigating these complex and sensitive issues. The disproportionate impact of the pandemic on minority ethnic communities has already underscored the urgent need to address systemic inequalities within the healthcare system. Failure to thoroughly examine the role of institutional and structural racism and inequality in the context of vaccine development and distribution would not only undermine the credibility of the Inquiry but also perpetuate existing disparities and injustices particularly in a context where Covid-19 infections and deaths still persist and a new pandemic could hit us at any time.
- 30. By prioritising the exploration of these issues, the Inquiry reaffirms its commitment to justice, equity, and transparency. Such an approach ensures that the investigation meaningfully incorporates the experiences and perspectives of those most affected by the pandemic, particularly ethnic minority healthcare workers and communities, who bore a disproportionate burden during this crisis.
- 31. A comprehensive examination of all potential factors contributing to healthcare disparities is essential to learning meaningful lessons and avoiding a repetition of past mistakes. This Inquiry

offers a unique opportunity to pave the way for systemic reform, ensuring healthcare resources and services are distributed fairly and equitably for all individuals, irrespective of ethnicity or background.

C. CONCLUSION

32. FEMHO acknowledges the comprehensive list of witnesses and appreciates the recent slight extension of the time frame for this module. We look forward to a robust examination of evidence and meaningful engagement with witnesses to ensure that the complexities of vaccine-related disparities are fully addressed.

33. FEMHO appreciates the full consideration of the Chair given to all the matters raised above. We are grateful for the attention paid to these important matters and remain hopeful that they will be carefully addressed within the inquiry process.

13 December 2024

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