IN THE MATTER OF THE UK COVID-19 PUBLIC INQUIRY

BEFORE BARONESS HALLETT

MODULE 4: WRITTEN CLOSING SUBMISSIONS FROM THE FEDERATION OF ETHNIC MINORITY HEALTHCARE ORGANISATIONS ("FEMHO")

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1. INTRODUCTION

1.1 The Covid-19 pandemic laid bare the structural and institutional racism embedded in the UK's healthcare system. Despite early evidence of disproportionate harm to ethnic minority communities, the government's response failed to adequately protect or engage these groups. The failures in vaccine rollout, engagement and clinical trials were not incidental; they were the product of systemic neglect that must now be confronted.

1.2 Module 4 specifically seeks to consider and make recommendations relating to the UK Government's development of Covid-19 vaccines and therapeutics and the implementation of the vaccine rollout programme in the devolved nations. These submissions represent the combined observations of FEMHO, after its review of the material disclosed, its participation in the public hearings and after taking time to reflect on its proposed recommendations for a better path forward, for its members and the public at large.

FEMHO's Membership and Advocacy

1.3 FEMHO is a consortium of over 55,000 individual members belonging to 45 organisations and networks. Our membership represents and advocates for the interests of health and social care workers ('HCWs') from minority ethnic communities across the devolved nations. At the heart of FEMHO's core principles and ethos is the conviction that minority ethnic communities must be enabled to equitably benefit from the level of care that the UK provides to all its citizens. Structural racism, compounded with inadequate engagement, access and representation has significantly barred these communities from receiving the appropriate care they have a right to access and it is precisely this cost to lives and our commitment to seeing meaningful and lasting change, that drives our purpose in this Inquiry.

Structure of these Submissions

1.4 We have divided these submissions into 7 sections:

a. Introduction
b. Structural and institutional racism

c. Engagement with ethnic minority communities & its influence on vaccine uptake
d. Misinformation and disinformation
e. Diversity in clinical trials
f. Additional failures by the Government
g. Recommendations

2. STRUCTUAL AND INSTITUTIONAL RACISM

2.1 As part of Module 4, the Inquiry is exploring "Barriers to uptake" - FEMHO's firm position is that such "barriers" cannot be honestly addressed without first acknowledging the damaging effects of the structural and institutional racism that has for so long permeated our healthcare system.

2.2 Therefore, in our view, the first task of this Inquiry and in respect of its investigation into these "barriers" is to acknowledge that the UK's systems have repeatedly enabled a disparate and unequal level of service for its citizens based on race, and that the pandemic response and rollout scheme was no different to that.

2.3 The issue is perhaps best described in the Elsevier Report, disclosed in Module 4, which studied *'Racism as the fundamental cause of ethnic inequities in COVID-19 vaccine hesitancy'*. The report defines institutional racism as being *"embodied in discriminatory policies and norms embedded in institutional structures [that] captures a broad array of practices that perpetuate differential access to goods, services, and opportunities within institutions."* [INQ000472267/1].

2.4 FEMHO notes that the same differential access, resulting from the same institutional structures, impacted the Government's vaccine rollout programme; be it in relation to engagement, clinical trial diversity or disproportions in vaccine uptake, we have seen how institutional level factors propagate racial disparities. There needs to now be a clarion call from this Inquiry that states clearly and boldly that structural and institutional racism are fundamental injustices we can no longer afford to obfuscate around. FEMHO invites the Chair to take decisive action by highlighting the issue and asking that the Government effectively tackles the matter head on.

2.5 FEMHO are encouraged that in Module 4, the concept of structural racism was acknowledged and discussed in evidence by multiple witnesses and experts alike who affirmatively took a stand on the issue; Dr Salman Waqar (FEMHO) kick-started the debate

at the oral hearings when he expressed salient views on racism, systemic discrimination and the need for representation in the *"committees or parts of government that are making decisions"*:

> *"We have found it a concerning and consistent issue that the issue of racism is one that is just not discussed. We seem to skirt around it, around the issue of should people have vitamin D or not, [and] as we heard in earlier modules should people be prioritised or not for the vaccination based on issues other than race; should people get access to PPE because they wear beards, or not? But the issue of race still seems to be one that we are still quite squeamish about to discuss, and I think it's a very important issue for us to discuss because, as we have heard, it's one that consistently comes up and the lack of our ability to be at these top tables to make some of these decisions means that we are not able to bring all of this information that I'm able to tell you now effectively into those spaces."* [3/17/3 – 3/17/18]

2.6 Matt Hancock, former Secretary of State for Health and Social Care, built on his own views from Module 3, where he opined that institutional racism was *"something [he] was already worried about"*. Adding that *"the ability to tackle something deep-seated like that is very hard but I had raised the issue and brought in a series of measures essentially about empowering people to speak up."* [36/145/6 – 36/145/10]

2.7 The Inquiry later heard from Dr Tracy Chantler, Expert in vaccine delivery and disparities in coverage, who referred to historical injustices as being *"the elephant in the room"*. Noting that *"unless you talk about it, you're not going to take any action"*. [10/196/8 – 10/196/9]

2.8 Dr Chantler later elaborated on this point in a way that we feel resonated with viewers wanting to understand the gravity of the structural issue:

> *"Addressing barriers, increasing access is key and very important, and still also needs to be done with the relevant underserved communities. However, there are foundational issues that will -- might need other trust-building exercises in that, as we've already seen, that some communities that have, you know, been recipients of structural discrimination, only to name Windrush or others, you know, in order for them to trust government, to trust a vaccination programme within a pandemic context, where it's very much seen as a government acting into people's private lives, you need to really address some of those structural issues, and that needs to start with conversations that lead to action."* [10/195/15 - 10/196/3].

2.9 Dr Heidi Larson, Expert in vaccine hesitancy and confidence, dedicated an entire section of her report to evaluating the impact of structural racism on the vaccine rollout, referring crucially to its "legacy of mistrust":

"In short, there exists a legacy of mistrust among ethnic minorities in the UK (and the US) and ongoing discrimination which shapes their perspective on the health and wider governance systems (Abba-Aji, 2022). And clearly, a continuation of underrepresentation of ethnic minority groups in medical research will perpetuate historical distrust in healthcare processes and presents a risk of unknown differences in efficacy and safety of vaccines". [INQ000474705/41]

2.10 Kemi Badenoch, former Minister for Equalities, similarly referred to the essential need to embed equality throughout government systems, which she says she tried to instill when she took her role in Government:

"Every government minister, every government department, has to deal with equality. It's not something that only one – that only one minister should be looking at, or only a certain set of ministers. It's like having a risk officer or a risk minister. Everyone should be assessing and managing their own risks; everyone should be following the Public Sector Equality Duty". [9/35/10 - 9/35/17]

2.11 FEMHO considers her statement can only be underscored in times of great urgency and impact, such as a pandemic.

2.12 Yet it was not without irony that during the time of the pandemic, the Sewell report, released in March 2021 and compiled by the UK Government's Commission on Race and Ethnic Disparities[1] denied the existence of institutional racism, thus losing a watershed moment for change. The report argued that prefixes like *"institutional, structural and systemic"* are only *"adding to the problem"*[2], which we say is indicative of an unhelpful approach to building trust within ethnic minority communities.

2.13 We contrast this report with the notable findings of Baroness Doreen Lawrence in "An Avoidable Crisis"[3], in which she too, around the same time as the Sewell report, conducted a review on the disproportionate impact of Covid-19 on Black, Asian and Minority Ethnic

[1] Commission on Race and Ethnic Disparities – Commission on Race and Ethnic Disparities: The Report – March 2021
[2] Ibid, page 34
[3] An Avoidable Crisis, October 2020

communities. Yet, Baroness Lawrence drew starkly different conclusions on the matter of institutional racism:

> *"Black, Asian and minority ethnic people have been overexposed, under protected, stigmatised and overlooked during this pandemic – and this has been generations in the making. The impact of Covid is not random, but foreseeable and inevitable – the consequence of decades of structural injustice, inequality and discrimination that blights our society. We are in the middle of an avoidable crisis. And this report is a rallying cry to break that clear and tragic pattern. It will require systemic solutions to systemic problems. It is not enough for policymakers to know that ethnic inequalities exist. We need to honestly confront how inequalities at all levels of society have come to exist and the intersectional impact it has on each ethnic group. This means recognising the interaction of faith, class, gender, disability, sexuality, ethnicity and culture in order to truly understand that no community is ever one homogeneous group."*[4]

2.14 FEMHO agrees with the principles laid out in Baroness Lawrence's report, which are unquestioningly also borne out in the evidence. We ask that the Inquiry bear these principles in mind, as well as the legacy of the Black, Asian and Minority Ethnic HCWs who died, including the first 10 doctors to die at all from Covid-19 who were from ethnic minority backgrounds, and look to address the matter of institutional and structural racism in its final report. This Inquiry presents as a unique opportunity to be a force for change in respect of our UK healthcare system and to make tangible impacts on it now. The opportunity is there to be on the right side of history; the cost not to is far too great.

3. ENGAGEMENT WITH ETHNIC MINORITY COMMUNITIES AND ITS INFLUENCE ON VACCINE UPTAKE

3.1 FEMHO are heartened that matters relating to the encouragement of ethnic minorities to participate in clinical trials and the engagement of ethnic minorities to take up the vaccines have been designated key concerns in this Module. FEMHO hope the Inquiry will start its review with the underlying premise that these disparities were entirely foreseeable, as many Government witnesses seemed to acknowledge[5].

3.2 The evidence shows that the Joint Committee on Vaccination and Immunisation ('JCVI') took the position that an age-based approach to the vaccine programme would be the most beneficial to our society (i.e. most likely to result in faster delivery and better uptake in

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[4] Ibid, Page 4

[5] Dr Mary Ramsey [6/106/16 – 6/106/20], Clara Swinson [4/105/10 – 4/105/14], Nadhim Zahawi [9/110/9 – 9/110/17]

those at the highest risk), however it also acknowledged that Black, Asian and Minority Ethnic groups were among the highest at risk, suffering both higher rates of infection and higher rates of serious disease, morbidity and mortality.[6] Despite the age-based approach, the JCVI gave clear mitigating advice for NHS England ('NHSE'), the Department of Health and Social Care ('DHSC'), Public Health England ('PHE') and the devolved administrations to work together to ensure that inequalities were still identified and addressed in implementation, which was supposed to include *"culturally competent and tailored communications and flexible models of delivery aimed at ensuring everything possible is done to promote good uptake in BAME groups and in groups who may experience inequalities in access to, or engagement with, healthcare services. These tailored implementation measures should be applied across all priority groups during the vaccination programme".* [INQ000234638/6].

3.3 The Government agreed to follow the JCVI's approach, but we say, fell short on achieving its stated aims. Whilst Government witnesses are steadfast in praising their efforts in getting a large proportion of the population vaccinated, their record in relation to ethnic minority engagement and uptake is far less defensible. The Government's narrative on this has been to acknowledge that their outreach methods were lacking but then seek to justify it as them having done *"everything we possibly could"* [3/102/12] under the 'novel' circumstances they found themselves in.

3.4 FEMHO have long argued that this tactic, to attempt to absolve themselves of wrongdoing in this way, plainly misunderstands the concept of responsibility, as it encourages fact finders to look for blame elsewhere when the responsibility of reaching at-risk groups rests solely with the Government. As Dr Waqar said *"it externalises the problem that it's not us, that we need to do more, that it's those communities, that they need to do more".* [3/18/15 - 3/18/17]. Further, groups such as FEMHO have been lobbying for better engagement long before the pandemic and opportunities have repeatedly been missed to build relationships and put in place outreach structures that would have helped in any emergency situation.

3.5 To rectify these shortcomings now, FEMHO proposes the establishment of permanent, proactive engagement frameworks that ensure a continuous, open-door dialogue with ethnic minority communities. These frameworks should integrate community leaders and healthcare professionals from these communities into the planning stages of health

[6] [INQ000071949/5]

initiatives, not merely as an afterthought but as a standard operational procedure. This approach will facilitate the early identification of potential engagement barriers and allow for the design of tailored, culturally sensitive health campaigns.

3.6 In addition, assessing the impact of policies introduced during the pandemic is also crucial. Initial measures like the Community Champions Scheme ('CCS') may have laid out a foundational framework for targeted engagement, however, an examination of their practical effectiveness reveals significant shortcomings. The CCS, which cost around £23 million to implement, was introduced as one of the Government's *"more ambitious package proposals"* [INQ000090144/1], and yet many of FEMHO's thousands of members could not even recall the scheme's existence [IN0000485278/18], and despite its introduction in October 2020, uptake amongst ethnic minority communities continued to be a concern throughout the rollout.

3.7 It was abundantly clear from early on that Covid-19 impacted ethnic minority individuals at a much higher rate than the White population. On that basis, it ought to have been incumbent on the Government to ensure that these groups were a primary focus to factor into planning for the rollout.

3.8 As early as February 2021, at a Vaccine Deployment meeting the then Prime Minister, Boris Johnson noted that *"uptake rates amongst Black ethnic groups, and especially Black African, was worryingly low"* [INQ000479211/1]. In April 2021, only 62.2% of all adults, those aged 18 or over, of Black African ethnicities, had been vaccinated compared to 93.2% of White British and 87% of people of Indian ethnicities [INQ000474623/57],

3.9 Even more concerning was the fact that just over 65.6% of Black African people aged over 80 were vaccinated in England, compared with 97.4% of White British people, and given that being 80 or more constituted the second priority group, this was declared a matter of *"major health concern*" [INQ000474623/55].

3.10 It is around this time, April 2021, that Boris Johnson called for a need to increase *"BAME uptake",* noting that *"the gap between White groups and others was not reducing."* [INQ000063687/1]. Two months later, in June 2021 he called for investment in *"conversations with hesitant people"* [NQ000479235/1] as the situation had not improved.

3.11 The level of coverage broadly across Black African ethnicities did not reach 75% until June 2022, and in the same time period, Black Caribbean adults who had received two

doses was just 59%, profoundly lower compared to the White British population by this date (90.3%).

3.12 Drs Kasstan-Dabush and Chantler reported that attempts were made to reduce disparities and affirmed that what separates the Covid-19 vaccination programme from routine immunisation programmes was the use of flexible funding models and commissioning frameworks that allowed never-before-seen levels of resources to be rapidly disseminated for tailored communication [INQ000474623/6]. However, they say, *"issues of trust and misinformation remained for some populations"* and ultimately *"the evidence indicates that there were insufficient strategies in place ahead of roll-out to prepare those considered less likely to be vaccinated"* [INQ000474623/6].

3.13 In fact, the evidence shows that the Government's efforts to reach minority communities, notwithstanding the knowledge that they were among the lowest in confidence and some of the highest at risk, was at best limited to a fragmented piece-meal approach. This is not just the opinion of FEMHO members who experienced the fragmentation first hand but also witnesses like Dame Catherine Bingham, former Chair of the Vaccination Taskforce, who lamented the Government on this issue.

3.14 FEMHO members report that, despite their readiness to help, their experience was one of rejection; of not being included in discussions and being kept at bay when offers to engage and/or support government efforts were made. Despite this, they persevered with their own individual efforts, in most cases with no Government backing or resource support because they knew what consequences their communities would face if they refrained. We also note the additional risk they faced in relation to the excess mortality rates of their HCW peers. Many significant groups committed significant time and effort, unpaid, outside of their working on the NHS frontline to help support vaccination efforts in their communities and networks. The following examples demonstrate this point:

3.14.1 The British Islamic Medical Association (BIMA) launched the BIMA Mythbuster series, a campaign led by trusted Muslim healthcare professionals to dispel misinformation and low confidence within Muslim and ethnic minority communities.

3.14.2 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 in an effort to fill the gap and ensure that ethnically diverse communities were reached and properly informed. Between them, they hosted numerous webinars, went on radio

shows and "phone-ins" to field queries and produce a wide array of content. Examples of events include the Core Covid-19 Vaccines Event from 16 March 2021, the BAME Vaccination conversation from 23 February 2021, the Covid-19 vaccination: The Journey So Far from 27 March 2021 and the BAME Covid-19 and the vaccine seminar from 11 February 2021.

3.14.3 The head of BAPIO Wales, Professor Keshav Singal was able to arrange for the Health Minister and the Chair of the MHRA to attend such a webinar and dispel myths about the vaccine after he raised concerns with the government about low vaccine confidence in ethnic minority populations. Other groups, such as MDC, also ran pop-up vaccination clinics where people were invited to speak and address concerns about the vaccine.

3.14.4 These collective efforts had a significant impact on the overall success and uptake of the Covid-19 vaccination programme. As Dr Waqar noted at paragraph 9 of his Witness Statement, FEMHO's fundamental contention is that *"thematic within the government decision-making during the pandemic was a failure to seek and/or receive input from those of us on the frontline, who were representative of, and interacting with, ethnically diverse staff and communities. This culpable failure played a direct and compelling role in the disproportionate rates of infection, death and adverse health outcomes felt among Black, Asian, and Minority Ethnic HCWs and our communities. Indeed, this lack of meaningful engagement is a systemic and historic issue permeating society."* [INQ000485278/3]

3.15 In short, trusted voices could and should have been appreciated by Government as a valuable and ready resource to boost engagement, and not simply utilised in piece-meal approaches. In future, FEMHO submits there ought to be a well-resourced, co-ordinated support effort backed by central Government that would enable minority leaders to do targeted work to reach their own communities.

3.16 We know that when trusted voices *were* utilised and ethnic minority leaders *were* recognised, engagement increased and so did uptake. Dame Emily Lawson, NHSE National Director, gave a compelling example of this in her live evidence:

"We did also get some national approaches. So the Bangladesh Caterers Association approached my team directly to say, in the Bangladeshi community, almost everybody is connected to somebody in a restaurant so,…we provided support, but they cracked on and did it. They spoke to their own community, and one of the big successes of this is -- you've just looked at the data from 3 February -- between 7 February and 7 April, the uptake in Bangladeshi communities…increased fivefold, just in two months. Which

showed that if we found the right engagement and the right ownership in the local community, and individual communities, it made all the difference." [9/194/14 – 9/195/4]

3.17 This model of community-led initiative is not unique. It makes perfect sense that similar successes are achievable in community programs, where local leaders utilised their deep community ties and cultural understanding to significantly improve health communication and intervention outcomes. These models underscore the potential of empowering community figures to lead public health efforts, ensuring messages are both culturally resonant and widely accepted. The evidence in this module is clear that utilising trusted voices worked and FEMHO members stood ready and waiting to help in this regard.

3.18 A central theme that ran through Module 4 is about trust and the idea that building trust requires more than government messaging; it demands meaningful engagement led by trusted community leaders, who are better positioned to bridge the gap between institutions and the people they serve.

3.19 Yet, trust is a two-way process, how could one expect ethnic minority groups to have faith in their Government, when it seems their Government had little faith in them too?

3.20 By this we mean there was a fundamental failure to entrust community leaders to take control of public messaging and to lead the Government's approach on outreach. Instead, the Government were more concerned with controlling the narrative and mitigating against potential reputational damage. That meant they failed to see the bigger picture which in turn meant efforts to engage with at-risk subgroups were fragmented and uptake impacted.

3.21 FEMHO seek to emphasise that this needs to change. In a future pandemic scenario trusted voices need to be recognised and resourced to take up this important mantle. FEMHO recommends the implementation of robust monitoring systems that track the effectiveness of engagement efforts and vaccine uptake across different communities. These systems should provide real-time data to health authorities, enabling timely adjustments to strategies and ensuring that no community is left behind. Regular public reporting on these metrics would also increase transparency and build trust among minority communities.

4. MISINFORMATION AND DISINFORMATION

4.1 The issue of engagement and trust is also linked to the issue of misinformation and disinformation, which we know impacted confidence and uptake among ethnic minority

groups disproportionately. A contemporaneous study was completed by Elaine Robertson et al via the Covid-19 wave survey in 2021. With a weighted sample of 9,981 responses, it was reported that *"Black or Black British people were the ethnic group with the highest rate of vaccine hesitancy at 71.8%. Pakistani/Bangladeshi groups were the next most hesitant ethnic group with 42.3% vaccine hesitant, followed by those of Mixed ethnicity (32.4%). The ethnic groups with the highest intention to vaccinate were the White British or Irish groups (84.8% being likely/very likely to take a vaccine) and the any other Asian background group (86.1%)…"* [INQ000250199/3].

4.2 FEMHO note that there was a consensus amongst witnesses in Module 4 that trusted voices, again, were the optimal way to deal with this issue. For example, Dr Heidi Larson who pushed back on the idea that Government may have been best placed to tackle misinformation argued the following:

"I mean, I think it's fine to keep repeating coherent and important facts, but it's not going to help to address the mis- and disinformation…what is needed is to make information relevant to people's concerns and misunderstandings, but also, it's not just about the information, it's about the way it's communicated." [3/176/14 – 3/176/20]

4.3 Sir Chris Whitty, former CMO for England also talked about communication and in doing so referenced Dr Salman Waqar in his evidence:

"And one of your core witnesses [Salman Waqar] I thought made rather a very powerful point, that it is all very well there's people like me prancing around and putting up slides, that wasn't actually speaking to their community. And that's an entirely fair point. And just speaking more and more is not going to help that." [5/93/6 – 5/93/11]

4.4 Dr Waqar indeed talked in his evidence about the messenger being just as important as the message when it comes to groups who are already predisposed to a lack of confidence, through no fault of their own, but because of past experiences of disproportionate outcomes in other healthcare contexts. Take for example, Black women who are 3-4 times more likely to die during childbirth or sickle cell carriers who are at risk of discriminatory treatment in their care by the NHS. FEMHO members found themselves taking on the mammoth task of having to dispel misinformation and disinformation about the Covid-19 vaccine, whilst trying to combat hesitations and fears around safety, all with the weight of those important health disparities and contexts in mind.

4.5 FEMHO assert that this is exactly the reason why trusted, recognised voices and community leaders are best placed to tackle such conversations; not only are individuals

in FEMHO respected professionals in their own right, they also have vested interests and connections to the communities they live in and serve.

4.6 To tackle the roots of misinformation effectively, it is essential for health authorities and government to collaborate with technology companies that host platforms where misinformation spreads and utilise trusted voices for messaging. Partnerships should aim to enhance algorithms that detect and limit the reach of disproven health claims, especially those targeting ethnic minority communities. These collaborations can also facilitate the promotion of verified health information, making it more accessible and prominent.

5. DIVERSITY IN CLINICAL TRIALS

5.1 In respect of diversity in clinical trials, FEMHO seek to remind the Inquiry of some of the concerning statistics we heard of in Module 4:

5.1.1 Over 90% of participants in the AstraZeneca 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 [INQ000474703/20].

5.1.2 The Vaccine Task Force's (VTF's) October 2020 press release noted only 7% of volunteers to the NHS registry were from ethnic minority groups [INQ000479019/78]. By December 2020 it had risen to only 8% [INQ000128474/20].

5.1.3 We also heard that on a structural level, there is currently no requirement for clinical trial investigators to report enrolment strategies or to ensure diverse recruitment. Despite some witnesses confirming in live evidence that they would welcome and would have benefited from such requirements [INQ000474705/41-42].

5.2 FEMHO's firm position on the matter of diversity in clinical trials is that addressing underrepresentation in clinical trial participation must be a priority for this Inquiry if it is going to deal with the issue of structural racism meaningfully. There is of course a clear causal link between poor engagement, underrepresentation in clinical trials, low confidence and therefore low levels of uptake in the vaccines. Addressing under-representation in clinical trials marks one entry point to help break that complex cycle.

5.3 In connection to this, FEMHO also seek to rebut any suggestion that diversity is unattainable if we are to conduct trials at speed in a pandemic context. FEMHO believe that this is a wrong way to approach the issue, rather, vaccine companies should prioritise conducting clinical trials at speed that also have a participation that broadly reflects the society it aims to vaccinate. When mechanisms are in place to ensure proportional representation in clinical trials is a standard requirement, vaccine companies will not have to worry about prioritising one over the other because the system should mandatorily work for itself.

5.4 It only underserves already disproportionately impacted communities if pharmaceutical companies are given a green-light excuse themselves of both priorities. It also opens up the possibility of arguing the same for all other areas of a pandemic response, i.e. engagement efforts, data monitoring and improving uptake rates, whereby a need for speed is said to necessarily take precedence over these things. If those arguments succeed, then there becomes no need to make any changes.

5.5 Best practices models would involve targeted outreach programmes and community partnerships established outside of emergencies to lead to significant improvements in diversity recruitment. These programmes would include collaborations with community health workers and local leaders who would facilitate trust and communication, which proves crucial for successful engagement with diverse populations.

5.6 FEMHO also raised concerns in our oral closing submissions about companies simply outsourcing diversity overseas to countries such as South Africa or Brazil. While providing data on certain ethnic groups, this methodology fails to address the unique challenges of mistrust, vaccine hesitancy, and systemic inequities faced by ethnic minority communities within the UK. The government and vaccine companies fundamentally misunderstood the nature of low confidence, treating it as a purely biological issue. They assumed that proving safety in Black populations abroad would automatically translate into trust among ethnic minority communities in the UK.

5.7 However, as FEMHO stated in its oral closing submissions *"vaccine mistrust is not just about biology—it is deeply rooted in historical injustices, systemic racism, and lived experiences of unequal treatment in healthcare."* [12/117/8 – 12/117/11]

5.8 Minority ethnic communities in the UK have distinct experiences shaped by historical and systemic discrimination, as well as unique cultural and social factors. Clinical trials

conducted abroad cannot replicate the nuanced trust-building that is required within UK communities. Building trust domestically requires transparency, local representation, and partnerships with community leaders here in the UK.

5.9 To meaningfully address this issue, there must be enforceable measures to ensure that clinical trials in the UK actively recruit and represent ethnic minority communities. This could include targeted outreach, collaboration with trusted community organisations, and transparent reporting on diversity metrics.

5.10 We must avoid the oversimplification of racial and ethnic identities. While communities of colour globally may share experiences of racism, the causes and manifestations of mistrust are deeply shaped by their local histories and social systems. One size does not fit all, and it is essential to design UK-based solutions for UK-based challenges.

5.11 Best practices models would involve targeted outreach programs and community partnerships to lead significant improvements in diversity recruitment. These programs would include collaborations with community health workers and local leaders who would facilitate trust and communication, which proves crucial for successful engagement with diverse populations.

6. ADDITIONAL FAILURES BY THE GOVERNMENT

6.1 FEMHO posits that whilst the vaccination programme provided generally positive outcomes, the Government let itself down in respect of ethnic minority interests in multifactorial ways. FEMHO would be remis not to mention the following additional failures:

6.1.1 The Yellow Card Scheme

6.1.2 The Yellow card system whilst useful unfortunately suffered in its effectiveness by, for example, not being available in multiple languages, thus alienating non-English speaking volunteers, it was also reportedly difficult to locate online and failed to record ethnicity or occupation. Dr Salman Waqar on Day 3 of the oral hearings, opined on the awareness and effectiveness of the Yellow Card system in this regard [3/9/2 – 3/10/1], as did other witnesses like Charlet Crichton of UKCV Family who on Day 6 of the hearings, reported that her members had raised many concerns regarding the Yellow Card system also [6/157/16 – 6/158/2].

6.1.3 Overall, the Yellow Card system would be strengthened by imparting better accountability, transparency, and reporting.

6.1.4 **Data collation and monitoring**

6.1.5 A lack of systematic inclusion of ethnicity data variables (e.g., surveys), as well as inconsistencies and inaccuracies in how ethnicity data was categorised and recorded in UK health data also had significant consequences for the vaccination programme. For example, Dr Heidi Larson notes that "*research by OpenSAFELY and the Office for National Statistics (ONS) diverged on data interpretation, arriving at differing conclusions about how ethnicity affected mortality. While methodological differences played a role, much of the discrepancy stemmed from inconsistencies in the datasets used (Wellcome, 2023).*" [INQ000474705/13]

6.1.6 We also heard Kemi Badenoch MP acknowledge that data was the "biggest challenge" for the Race Disparity Unit which she oversaw:
"So data was the biggest challenge. This might because the unit that I was overseeing, the Race Disparity Unit, was a data unit, so we would have been more interested, perhaps, in data than others. But we constantly encountered issues in just finding out what was going on. Sometimes that was because the data hadn't been collected in the first place so there was nothing to look at, and finding out whether it had or had not been collected could also be a challenge. So you didn't know whether there was something to see and we couldn't find it, or there was nothing to see." [9/45/12 – 9/45/23]

6.1.7 She discussed ways in which the paucity of data hindered the Unit's ability to assess and respond to downward trends, one example was particularly striking, which related to ethnic minority HCWs that were already bearing the brunt of systemic failures in planning whilst being under-protected on the frontlines:
"There was a shortage of data. Just because there's lots of data, doesn't mean that it's what you're looking for. So in terms of if you're talking about volume, yes, there was lots of data. But I remember us trying to find out the ethnicity of people who had been dying, especially the frontline ethnic minority workers in the NHS. We didn't have that. So my first quarterly report I think talked about the mandatory collection of that sort of data." [9/47/5 – 9/47/13]

6.1.8 However, even by December 2021, at the time of Ms Badenoch's 4th quarterly report in the 2nd year of the pandemic, she was still calling and making the same recommendations for relevant health departments and agencies to review and action existing requests for health data [INQ000089747/8].

6.1.9 Data issues, particularly regarding a lack of ethnicity data, have been a recurring theme in the Inquiry thus far. The telling revelations by witnesses like Kemi Badenoch who suggest quite openly that interdepartmental politics, rather than any reasoned approaches are what hindered data sharing between government agencies, is deeply concerning.

6.1.10 FEMHO agree with the conclusions drawn by Drs Kasstan-Dabush and Chantler that better data systems need to be put in place for adequate evaluations in future [10/202/2 – 10/202/3].

6.1.11 **Language**

6.1.12 FEMHO also wish to make mention of this issue - not only has the *"hard to reach"* mantra been repeated in this module, we saw the use of this language being taken a step further with phrases like *"hardest to reach"* [9/57/12] being used and the dismissing of what are clearly long-standing issues, as people having *"lower"* levels of education [9/72/23 – 9/72/24], living in *"closed"* communities [9/72/22 – 9/72/23] or coming from countries with *"authoritarian"* mindsets that is causing distrust [9/72/9 – 9/72/15]. These statements all came from the former Minister of Equalities no less. It is FEMHO's firm position that these attitudes must change if building trust and sustaining trust is going to be achieved.

6.1.13 Dr Heidi Larson made this point clear in her evidence about the phraseology of "vaccine hesitancy". Notably, she was the only witness to be asked whether the terminology in this respect matters. In response, she said: *"Yes…Confidence is a positive sentiment…and hesitancy is a state of indecision".* [3/123/2 – 3/123/3]

6.1.14 It was assuring that Lady Hallett intervened at this stage by asking *"and scepticism goes one step further, right?"* to which Dr Larson said "*Yes".* [3/123/7 – 3/123/9]

6.1.15 Whilst it has been encouraging to see that the Chair and Inquiry team have been alive to ours and other core participants concerns raised around this language. The fact that Dr Larson was the only witness throughout the Module 4 hearings to be asked about the importance of this terminology, whilst at the same time we heard witnesses like Kemi Badenoch use this language repeatedly, was discouraging. Matters such as these may appear less grandiose but we say go to a much deeper issue; words are important.

6.1.16 In light of these concerns, FEMHO recommends the implementation of regular language audits for all public health communications. These audits should be conducted by panels including community representatives and linguistic experts, and available in different languages, to ensure that all messaging is empowering, inclusive, and devoid of any terms that could alienate or stigmatize the very communities they aim to serve. This approach not only promotes sensitivity but also actively involves community voices in shaping public health narratives and trust those narratives.

6.1.17 **The Full Circle Argument**

6.1.18 Finally, we wish to remind the Inquiry of the "full circle" argument that FEMHO's Lead Counsel, Leslie Thomas KC, raised in oral closing submissions. Racism is a fundamental starting concern in regards to disparities in vaccine uptake. When the issue is ignored, the cycle repeats itself and minority groups continue to be impacted in multiple different ways, by multiple different facets. We recount the cycle here as a concluding reminder for the Inquiry:

"It all starts with the fact that pre-existing health inequalities and historic mistrust are unaddressed, despite them being foreseeable…
Which in turn means there is poor engagement with minority ethnic communities in respect of the national vaccine roll-out scheme…
Which then causes poor diversity in clinical trials, low trust in the vaccines and low uptake by these same communities…
Which means sentiments harden and there is a general growth in vaccine hesitancy or lack of confidence…
Which means the Government then needs to consider policies like 'Vaccination as a Condition of Deployment' to drive uptake…
Which might increase uptake in the short term but has a knock-on effect of building and reinforcing distrust.
Which means, coming full circle, that there is an impact years to come regarding vaccines, trust in government and perpetuating and worsening health inequalities in our society.
This vicious cycle must be broken. Without systemic reform and continuous, sustained meaningful engagement, these issues will reoccur with future public health crises." [12/115/22 – 12/116/18]

6.1.19 The Inquiry team *may* feel these weighty issues are simply beyond their scope to address, however we say the cycle of mistrust and poor health outcomes can be interrupted by small steps. By transforming our approaches, we can begin to rebuild trust and thereby improve the efficacy of public health initiatives. Clear, respectful and inclusive language not only enhances engagement but also supports the development of policies that are better received and are more effective in addressing the health needs of all communities. From seemingly small and simple steps such as these a much larger transformation can be achieved; little by little, a little becomes a lot.

7. Recommendations

7.1 In addition to the recommendations as stipulated in the Rule 9 Witness Statement of Dr Salman Waqar submitted on 6 June 2024 in respect of this module, FEMHO make the following recommendations:

- **Acknowledge that structural racism is a fundamental cause of racial disparities** – In 1999, the MacPherson Report recognised institutional racism within the Metropolitan police force, marking a pivotal moment for systemic change in law enforcement in the UK. Drawing from this historical precedent, it is imperative that in 2025, this Inquiry similarly recognises structural racism as a root cause of health disparities. Such a declaration would not only acknowledge the depth of the problem but also compel government bodies to adopt this framework in all health-related policies and training programs. The Inquiry should take this bold step, supported by the consensus of several witnesses and the robust evidence presented in Module 4, to formally declare and address the structural racism that pervades our healthcare system.

- **Funding programmes for engagement services** – Funding should be made available to community and faith groups, and other recognised trusted voices to carry out information dissemination work and improve inclusivity. Said funding should also not be based solely on grants and, in the spirit of equity and innovation, should look to be contracts for services (in the same way that is done for vaccination contracts and contracts for Personal Protective Equipment). FEMHO argues this goes back to trust. Trust us to deliver the service, rather than continue to use the leash of a grant to stifle creativity, when the focus should be on outcome not process.

- **Utilise trusted voices** - We echo the point made by Dr Kasstan-Dabush of it being a necessity that those who are at highest risk with lowest confidence should be the ones involved in the mechanisms to engage their own communities. A situation where the Government is suddenly gathering people together that do not already work in partnership must not be repeated, instead the Government must develop and build on existing trusted relationships, which were and are already in place in some areas.

- **Create, update and maintain systems monitoring ethnicity data across Government** - Ethnicity data collected during vaccinations should be made a permanent, non-negotiable feature with departments strongly advised to permit sharing of data during a pandemic. It should be real time information, which will support analytical outputs and provide evidence of the health inequalities amongst ethnic groups so that effective recommendations can be made for policy and partner interventions.

- **Deploy enforceable measures to ensure that clinical trials in the UK actively recruit and represent ethnic minority communities** - Mandatory rules should be implemented to ensure adequate representation, something we note some or all of the vaccination company witnesses confirmed they would welcome[7].

- **Increased efficiency, transparency, and easier access to safety monitoring systems such as the Yellow Card Scheme** – Enhance the Yellow Card Scheme to include multilingual support and proactive outreach components to ensure it is accessible to all UK residents, regardless of language proficiency. The accessibility features of this system should be regularly reviewed and updated as appropriate. Safety data on novel therapies such as vaccines and antivirals should be publicly available to help increase confidence.

- **Implement a future inclusive vaccination taskforce** - FEMHO agrees with witnesses who have said that collaboration between Government, the private sector and community interest groups is important to any future pandemic response. FEMHO robustly says that any future taskforce would need to include community voices who can speak directly on these boards to minority issues. FEMHO welcomes the comments of Professor White who, in his evidence, suggested FEMHO might be such an organisation that could suggest trusted voices to join [12/38/11 – 12/38/20].

[7] Darius Hughes, Moderna [9/20/1 – 9/20/17], Ben Obsborn, Pfizer [8/135/21 – 8/135/25]

FEMHO agrees such a future taskforce should be formulated in peace time to give it the best chance of contributing to effective preparedness for any future pandemic.

- **Investment in research and development** - of therapeutics specifically designed and tested to meet the unique physiological characteristics and health conditions prevalent among minority ethnic populations. We are concerned at the continued lack of R&D in this area, and more widely as it concerns the effectiveness and inclusiveness of algorithms and AI, as well as questions around whether there needs to be ethnicity tailored treatment plans in certain circumstances given it has been recognised that pathophysiology differs based on ethnicity.

- **Recognition of the everyday heroes –** This regards those trusted voices who were working tirelessly despite additional risks and much higher rates of mortality to help support the rollout and who received little recognition for their efforts, let alone support. Those who, in spite of the permeating inequalities, the health risks and other hinderances, took the approach of banding together, following Government advice and helping their communities to understand and do the same. They did more than their bit to help save lives. This recommendation is relevant to this module because it is in line with FEMHO's interests, i.e. to implore the Government to do better in supporting, resourcing and recognising trusted voices like ours in future.

8. CONCLUSION

8.1 FEMHO trusts that these recommendations will provide the Inquiry with actionable paths to address the significant issues uncovered. It has been committed to not only participate in but to actively support and guide the Inquiry towards outcomes that substantially and sustainably improve public health, particularly for ethnic minority communities. It is FEMHO's sincere hope that the Inquiry will adopt these recommendations and commit to their implementation, ensuring that the lessons learned will lead to lasting change.

14 February 2025
Leslie Thomas KC
Elaine Banton
Saunders Law