UK COVID 19 INQUIRY: MODULE 4

WRITTEN CLOSING SUBMISSIONS ON BEHALF OF THE MIGRANT PRIMARY CARE ACCESS GROUP ('MPCAG')

I. INTRODUCTION AND CORE PROPOSITIONS:

- These submissions supplement MPCAG's Rule 9 statement dated 4 October 2024,¹ opening written submissions dated 13 December 2024,² opening oral submissions made on 14 January 2025,³ closing oral submissions made on 31 January 2025,⁴ and the live testimony of Miss Anna Miller (on behalf of MPCAG) on 15 January 2025.⁵
- 2. MPCAG, composed of Doctors of the World UK (DOTWUK), Kanlungan Filipino Consortium, the Joint Council for the Welfare of Immigrants (JCWI) and Medact, specialise in supporting migrants to access healthcare services. They were at the forefront of efforts to access the vaccine and therapeutics on behalf of their clients during the Covid-19 pandemic. Their expertise and insight into what was happening on the ground, including their unheeded calls on Government to do more to remove barriers given the consequent harm caused to migrants, is deserving of careful consideration and significant weight.
- 3. Poor Government communication and lack of engagement with trusted migrant NGOs, whilst relevant and noteworthy, were in truth peripheral failings when examined in context and set against the evidence. Rather, front and centre, and an issue with which the Inquiry must now grapple, was the insidious deterrent effect of the Department for Health and Social Care's (DHSC) Charging Regulations and data sharing practices, and the encroachment of immigration enforcement into healthcare policies.
- 4. MPCAG does not stand alone in the incontestable identification of these two factors being the root cause of barriers to vaccines and therapeutics uptake for migrants during the Covid-19 pandemic. Resoundingly and importantly, the Inquiry's own experts agree with this assessment.

¹ INQ000474407 – MPCAG Rule 9 Witness Statement.

² INQ000474801 – MPCAG Opening written submission.

³ Transcript of 14 January 2025 [39/12] - [42/13].

⁴ Transcript of 31 January 2025 [12/7] - [15/25].

⁵ Transcript of 15 January 2025 [86/5] – [112/17].

5. Professor Heidi J. Larson⁶ and Dr Ben Kasstan-Dabush together with Dr Tracey Chantler⁷ were instructed by the Inquiry to provide their expert view on the topics of 'Vaccine Hesitancy and Confidence' and 'Vaccine Delivery and Disparities in Coverage' respectively. Their reports were comprehensive, evidence based and compelling. Critically, both experts made findings and recommendations that wholly validate and corroborate the evidence of MPCAG regarding the harmful impact of immigration healthcare policies and data-sharing on migrant access to life-saving vaccines and therapeutics that exacerbated pre-existing healthcare inequalities during the pandemic:

"For example, among migrant communities, this mistrust is in part owing to the 'Hostile Environment' policies which aim to make life difficult for migrants living in the UK (Joint Council for the Welfare of Immigrants, 2024)..._Although Covid-19 treatment and vaccinations were exempted from the charging provisions, this practice has fostered a pervasive sense of mistrust and suspicion toward the NHS which intensified during the pandemic because the sharing of data from the NHS to the Home Office presented as a serious risk and fear of perceived or actual immigration consequences, thereby acting as a disincentive and causing many to avoid accessing the vaccine or therapeutics" [Larson at § 28]

"...People with insecure immigration status were not always aware that they were entitled to receive Covid-19 vaccinations free-of-charge (Deal et al., 2021). Some may have been aware that they were eligible to be vaccinated, but were concerned about being charged or facing immigration controls and checks if they presented for vaccination (Deal et al., 2021). This concern relates to established data sharing arrangements between NHS services and the Home Office (Deal et al., 2021)..." [Kasstan-Dabush at § 267]

6. In his opening submissions, Counsel to the Inquiry (CTI) Hugo Keith KC stated: "The evidence before you is clear that the stark disparities of Covid coverage, which is what they were, amongst minority ethnic groups, were rooted in inequality rather than difference... Access barriers, rather than refusal, was obviously the primary barrier to vaccination for many of those communities."⁸

⁶ INQ000474705 - Vaccine hesitancy and confidence during the Covid-19 pandemic - Prof. Heidi J. Larson (Lead Author).

⁷ INQ000474623 - Vaccine Delivery and Disparities in Coverage - Dr Ben Kasstan-Dabush and Dr Tracey Chantler.

⁸ Transcript of 14 January 2025 [52/4] – [52/12].

- 7. Yet, at no point in the written or oral evidence provided by senior Government ministers did the Inquiry receive clear or cohesive evidence of any unified approach to addressing, let alone dismantling, those barriers to access to vaccines for migrants:
 - i. **Matt Hancock**, former Secretary of State for Health and Social Care (the Minister in charge of the DHSC and all its laws and policies from 2018 to 2021) when asked about barriers to vaccine uptake and inequalities stated, in no uncertain terms: "Yes, we did everything we possibly could, yes. And of course, you know, I'd leave no stone unturned." He then relied on the Queen being vaccinated as being "a very positive proof point." Disregarding the absurdity of citing the Queen's vaccination status in response to a question on healthcare *inequalities*, his claim that "no stone was left unturned" invites scrutiny and when examined does not withstand such scrutiny. Notably, throughout both his oral testimony and extensive 70-page witness statement, he fails to acknowledge (let alone consider) two pivotal issues of concerns for his department: NHS charging and data-sharing with the Home Office terms that remain conspicuously absent from his account.
 - ii. Nadhim Zahawi, then Minister for Covid-19 Vaccine Deployment, recognised that "it's in the nation's public health interest that we vaccinate all groups".⁹ He accepted that the perception that people may be charged (under the DHCS's charging regime) or that information might be shared (with the Home Office) was a deterrent to accessing the vaccines. When asked whether enough was done to communicate [to migrants] that they would not be charged and information would not be passed on, he referred to his appearances on news media and radio saying "...I'm the minister, you know, I'm basically saying to you: look, just walk in and get vaccinated, get protected, and you're safe and you don't have to fear the state, effectively.¹⁰ Not only was that statement misleading, given that categorical assurances could not be made regarding the non-disclosure of data to the Home Office, as the data-sharing requirements under the Charging Regulations remained in force - but it also underscored a fundamental shortcoming: it revealed that communication alone represented the apex of the Government's response which was in any event only aspirational, while failing to engage with the underlying structural causes of fear and mistrust.
 - iii. Finally, **Kemi Badenoch**, then Minister for Equalities, in the Equalities hub within the Cabinet Office, was charged with setting the example for the rest of Government

⁹ Transcript of 27 January 2025 [115/16] – [115/17].

¹⁰ Transcript of 27 January 2025 [112/17] - [116/7].

on anti-discrimination standards, stated: <u>"We cannot adjust our health system, in</u> <u>my view, to undermine borders and border security. That would create loads</u> <u>of other problems. So that's just something that I think we need to accept</u>."¹¹

- 8. These examples collectively underscore a persistent lack of coordination, and indeed commitment or agreement at the highest levels of Government, revealing not only the absence of a unified strategy to eliminate barriers to vaccination for migrants but also a broader failure to identify, acknowledge and address the structural inequities that underpin these challenges.
- 9. To support those core propositions MPCAG's closing submissions are structured as follows: (1) Scope of Module 4; (2) Data on vaccine uptake disparity; (3) Identification of key Governmental failings that impeded vaccine uptake amongst the migrant community; and (4) Conclusion and Recommendations to prevent the recurrence of these failings in a future pandemic.

II. SCOPE OF MODULE 4 OF THE INQUIRY

- 10. On the issue of scope, MPCAG wish to firmly dispel any doubt as to whether the two main barriers to accessing the vaccine and therapeutics for the migrant community identified, namely the DHSC's Charging Regulations and their data sharing practices with the Home Office, fall within the parameters of the Chair's inquiry under this module.
- 11. MPCAG rely on the following incontrovertible facts:
 - i. The DHSC was the central government healthcare body at the epicentre of the Covid-19 vaccine operation.
 - Pursuant to s.1C of the NHS Act 2006, the Secretary of State for Health and Social care is under a duty, in exercising functions in relation to the health service, to have due regard to the need to reduce inequalities in *every* policy and action.
 - iii. Responsibility for the NHS Charging Regulations and associated data sharing practices falls squarely on the DHSC who both laid these Regulations before Parliament and are the singular government body responsible for their implementation.
 - iv. This Inquiry is concerned with public health. The DHSC is a public health body.Hence, the laws, policies and practices introduced and operated by the DHSC,

¹¹ Transcript of 27 January 2025 [62/3] – [62/6].

including those exclusively directed at migrants, are under the *direct* scrutiny of this Inquiry.

- v. Should the Inquiry, upon thorough examination of the evidence, including the assessments provided by the experts, determine that any laws, policies, or practices implemented by the DHSC were instrumental in creating obstacles to vaccine and therapeutic access, and/or actively undermined broader efforts to ensure equitable access, it is incumbent upon the Inquiry to formally acknowledge these findings in its report.
- Vi. Migrants make up a significant proportion of society. According to the 2021 Census, approximately 10 million people residing in the UK – equivalent to 16.8% of the population – had been born abroad.¹²
- vii. The success of any vaccination programme hinges on high uptake and inclusive access for all.
- 12. Module 4 Provisional Outline of Scope (September 2023) directs the Chair to identify "[t]hematic issues relating to unequal vaccine uptake" such as "identification of groups which were the subject of unequal uptake, potential causes of such unequal uptake and the Government response".
- 13. The official Terms of Reference for the Covid-19 Inquiry requires the Chair to consider "disparities evident in the impact of the pandemic on different categories of people, including, but not limited to, those relating to protected characteristics under the Equality Act 2010" – which encompasses migrants within the legally protected characteristic of race, which includes colour, nationality, and ethnic or national origins.
- 14. Paragraph 1 (a)(xx) of the Terms of Reference directs that the aim of the Inquiry is to look at the public health response **including immigration and asylum.**
- 15. MPCAG were designated Core Participant (CP) status on the basis that they have a significant interest in an important aspect of Module 4, namely *"barriers to vaccine uptake and whether vaccine delivery appropriately considered the needs of marginalised or vulnerable communities"*. The Chair additionally found that MPCAG could, among other things, *"aid the Inquiry in understanding the experiences and perspectives of those with uncertain immigration status and how and why this may have affected their access to vaccines."*¹³

¹² International migration, England and Wales, Census 2021.

¹³ Notice of Determination, Core Participant Application 17 July 2023.

- 16. Consistently, since they first outlined their view on barriers in their CP application in 2023, MPCAG have resolutely maintained that the DHSC's Charging Regulations and data sharing practices with the Home Office caused and risk causing irremediable harm to migrants in preventing and deterring access to vaccines and therapeutics.
- 17. MPCAG's closing submissions set out below, are now provided to assist the Inquiry in addressing these specific matters identified in the *Terms of Reference* and the *Module 4 Outline of Scope*. It now falls to the Inquiry to recognise the public health harm these vaccine barriers caused as a result of the DHSC's policies and practices and make robust recommendations to ensure that they are not perpetuated.

III. DATA HIGHLIGHTING DISPARITY IN VACCINE UPTAKE

- 18. Undeniably, the data shows a stark disparity with significantly lower vaccine uptake in BAME communities (emphasis added):
 - <u>All ethnic minority groups had lower first dose uptake</u> compared with the White British population, with the lowest vaccination rates among <u>Black African (58.8%)</u> and Black Caribbean groups (68.7%) followed by Bangladeshi (72.7%) and Pakistani (74.0%) groups. [Larson § 72]
 - The proportion of <u>Black Caribbean</u> adults in England who had received two doses increased slowly to <u>59% by June 2022</u>; this was profoundly low compared to uptake in the <u>White British population by this date (90.3%</u>). [Kasstan-Dabush § 2]. The visual of this disparity was starkly contained in Slide 7 of the CTI's opening slides in Module 4.¹⁴
 - iii. The ONS (2022) surmised that lower vaccination coverage in some ethnic groups in England was a contributing factor to the elevated risk of COVID-19 death and differences in vaccination coverage between the Black Caribbean and Black African ethnic groups and the White British ethnic group explain a large part of the excess risk of mortality [Kasstan-Dabush at § 83].
 - iv. CHIME data shows that adults resident in England <u>who do not speak English as</u> <u>a main language were less likely to have received two doses of Covid-19 vaccine</u> by June 2022 (74.9%) compared to adults who spoke English as a main language (88.5%) [Kasstan-Dabush at § 204].

¹⁴ INQ000474831 0007

- 19. Migrants from ethnic minority groups are significantly represented in these statistics.
- 20. The statistics demanded a proper and unblinkered interrogation by the Government of the underlying root causes for hesitancy on behalf of migrants.
- 21. As Larson stated in her report: "When there are declines in vaccine uptake, it flags an underlying problem which may be preceded by hesitancy, but also may be due to access issues, despite a willingness to get vaccinated." [Larson at § 38].
- 22. MPCAG highlight below the principal ways in which the Government abjectly failed to identify and/or remedy the fundamental issue, so clearly highlighted in the data, that migrants (both as a sub-set of BAME *and* as a separate group) faced considerable barriers to accessing vaccines.

IV. KEY GOVERNMENTAL FAILINGS

- 23. MPCAG consider that the barriers to migrants' access to vaccines and healthcare can be traced to four critical failings:
 - i. <u>First, the DHSC's Charging Regulations.</u> So long as the charging regime remained operational – mistrust, confusion and fear persisted. The narrow Covid-19 exemption was inadequate. It did <u>not</u> exempt charges for complications arising from Covid-19 or for long Covid thereby creating uncertainty and confusion in an already complex system rife with mistakes and racial profiling by those charged with operating it. The fear of being charged was directly responsible for deterring migrants from accessing the vaccine and treatment and trusts regularly made charging mistakes.
 - ii. <u>Second, data sharing by the DHSC</u>. The DHSC's policy *mandates* the sharing of patient data with the Home Office for NHS debts *and* immigration checks. This fostered deep mistrust among migrant communities, deterring them from seeking vaccines and therapeutics for fear of immigration consequences and enforcement. Despite widespread acknowledgment of this issue, the DHSC refused to implement a data-sharing firewall to protect *all* patient data during the pandemic.
 - iii. <u>Third, exclusion from vaccine invitation and booking.</u> The vaccine rollout model, which relied (i) initially on GP registration and records for early invitation <u>and</u> (ii) subsequently on NHS numbers to book a vaccine appointment, excluded many vulnerable migrants who had either been refused GP registration or been deterred from registering with a GP for fear of charging and data-sharing. Long before the pandemic, the Government were aware of this issue. Efforts to inform the public that

vaccines could be accessed without an NHS number were only undertaken at later stages and were inadequate.

- iv. <u>Fourth, failure to build trust and refusal to remove barriers</u>. External warnings from frontline migrant organisations fell on deaf ears. Internal warnings, including from the top Chief Medical Officer Sir Chris Whitty, went unheeded. The Government refused to act on critical recommendations to build trust and remove the above access barriers for migrants either during the pandemic or since. These harmful barriers persist.
- 24. At the core of these barriers lies a pervasive distrust, often compounded by fear, shaping many migrants' perceptions of the Government and other state institutions. This mistrust extends to the NHS, largely due to the DHSC's role in enabling the incursion of punitive immigration policies, targeted exclusively at migrants, into the healthcare system.
- 25. This mistrust a prominent theme that has forcefully emerged across all evidence in Module 4 - is longstanding and was clearly well-known to the Government, as outlined by Dr Mary Ramsay in her evidence to the Inquiry.¹⁵
- 26. It was well-known because it did not arise by accident, but rather by design. Successive Governments have purposefully sought to perpetuate an atmosphere of fear and overt hostility towards migrants through various laws and policies, including access to healthcare which has created a legacy of mistrust. Whilst primary care was not the target of those policies and was excluded from that, the wider legacy impact remains.
- 27. The DHSC's Charging regime and the ongoing practice of data sharing between the NHS and the Home Office created an overwhelming deterrent effect for migrants. No communication strategy, regardless of its sophistication or reach, could begin to counteract the damage and mistrust inflicted by years of institutionalised hostility towards migrants in the healthcare setting that was generated by these two policies.
- 28. Government communication on this needed to be internal and cross-departmental as well as outwards to migrant communities, given the clear evidence before the Inquiry of misapplication of the current rules increasing fear and mistrust within the wider migrant community whether they are liable to charging or not.
- 29. Without comprehensive reform, these systemic failings will, without doubt, continue to undermine equitable healthcare access in future public health crises.

¹⁵ Transcript of 21 January 2025 [113/9-15] – [114/1-4] and reference to INQ000477091 Behavioural Science and Insight Unit_"*Barriers and facilitators to COVID- 19 vaccination uptake*", September 2021, p.17.

DHCS's Charging Regulations

- 30. The Inquiry has received substantial detail about the DHSC's charging regime. A comprehensive overview of the complexity of the regulations and the frequency with which incorrect charges are levied are set out at § 80-109 of MPCAG's Rule 9 Statement.
- 31. On 29 January 2020, COVID-19 was designated as a communicable disease exempt from charges.¹⁶ Whilst this meant that the vaccine and treatment of Covid-19 with therapeutics was free, any underlying health condition or complications arising from Covid-19 and long-Covid were not covered and remained liable to charges. *In practice,* it is well documented that even exempted charges, or those not liable to be charged, are frequently mis-charged due to the complexity of the Regulations. Further, the entire structure and system of the Charging regime remained operational throughout the pandemic. As such, for an NHS body to be satisfied whether charges for complications or long Covid were applicable, the usual immigration checks and data sharing of debts with the Home Office were required.
- 32. CTI's questions to Anna Miller appeared to imply that the charging regime is not itself a problem or barrier in public health terms because the vaccine and therapeutics were not subject to charges *per se*, but rather that the problem was instead a failure to take all necessary steps to communicate this exemption to migrant groups.¹⁷
- 33. Respectfully, this is an oversimplification and fails to appreciate the powerful deterrent effect of the charging regime and the fundamental historical mistrust bred by this regime. Miss Miller's evidence on this point was clear:

"....I think the keys things, takeaway things to understand about this [charging] policy is that its main impact is deterrents (sic). It keeps people who worry they might – it might be applied to them from going anywhere near healthcare services and it is partially -- it's partially because the risks associated with the policy are high. It's not just that you're going to get a large bill, if the NHS trust decides they're

¹⁶ By way of amendment to Schedule 1 (*diseases for which no charge is to be made for treatment*) of the National Health Services (Charges to Overseas Visitors) Regulations 2015/23 by inserting "*Wuhan novel coronavirus (2019-nCoV*)" from 29 January 2020 by Regulation 2 of the National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2020/59. This was later amended to refer to "Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2)" by Regulation 2(4) of the National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2022/19. Pursuant to an amendment made on 10 February 2020 to DHSC's guidance "NHS cost recovery - overseas visitors" the then-called "novel coronavirus (2019-nCoV)" was added to the list of exempt services.

¹⁷ Transcript of 15 January 2025 [96/3] – [93/13].

going to charge you, you get a large bill, and also a 50% fine for accessing that service; it's also that it carries the risk of being reported to the Home Office and for those ... who aren't migrants and might not understand, being reported to the Home Office runs the risk that you will be put into immigration detention and for some people it runs the risk that you'll be returned to a country that you fear for your own safety in. So this is why what we end up seeing as deterrents, is the risk is too high for a lot of people to go anywhere near healthcare services. And then ... because it's such a complex policy for individuals, it's nigh on impossible, before you enter a service, to know if you are going to end up being charged or not, because charges apply to some services, they don't apply to others, they don't apply to public health services. But -- this isn't a comment about migrant patients but all patients...people don't understand what type of service they're accessing in the first place, and clinicians always say patients present with symptoms without diagnoses, you might have a good idea of -- you know, you might be fairly confident that what you've got is an infectious disease and therefore you are not going to be charged, but you might not be right about that. It still carries a risk."¹⁸

- 34. For the following reasons, any suggestion that the DHSC's Charging regime was not, in fact, a barrier to vaccines and therapeutics because Covid-19 was exempt, is manifestly flawed.
- 35. <u>First</u>, as outlined above by Miss Miller, deep-rooted mistrust of the authorities meant that many migrants still *believed* there was a high risk of being charged if they accessed the vaccine or therapeutics. These fears could not be dispelled overnight so long as the Charging regime introduced as a deterrent and a penalty, as a whole, continued to operate. *Real fears* about being charged an unknown amount and potentially incurring an unpayable NHS debt, that could impact on future immigration applications, presented an overwhelming risk for some migrants that deterred them from accessing the vaccine and therapeutics for treatment.
- 36. <u>Second</u>, the Charging Regulations are extraordinarily complex. It is inevitable that many migrants foreign nationals not familiar with UK healthcare systems would be and were unable to distinguish between different types of services and exactly what falls within the remit of primary (free) or secondary and tertiary (not free, unless exempt) healthcare services. These systems are designed to be understood and navigated by healthcare professionals and relevant overseas charging teams in hospitals not patients themselves. Furthermore, as Miss Miller emphasised in her evidence, individuals seeking

¹⁸ Transcript of 15 January 2025 [93/23] - [95/7].

medical care present with symptoms, not a diagnosis, which may or may not fall within an exemption, creating uncertainty about whether their condition would fall within the exempted COVID-19 treatment. This uncertainty was exacerbated in the context of a novel coronavirus for which the range of symptoms (which were rarely static) were emerging in real time. The risk of only finding out whether respiratory symptoms were attributable to Covid-19 (therefore free), or complications from Covid-19 or another condition such as asthma or chronic obstructive pulmonary disease (COPD) (therefore chargeable), *after* a charge had been levied, was too high for many to take. Indeed, those with underlying health conditions or who were clinically vulnerable were *more* at risk of being charged as the distinction of where to draw the line on treatment for Covid versus treatment for related complications is far from clear.

- 37. Past experience in relation to Tuberculosis and HIV treatment had already shown that narrow charging exemptions have limited effect. Despite treatment for TB and HIV being exempt from charging, research corroborates that the existence of the wider Charging regime significantly deters access to treatment for migrants. It was therefore known *prior* to the pandemic that exemptions for vaccinations and infectious disease treatment alone were insufficient.¹⁹
- 38. The most powerful piece of evidence before the Inquiry, that corroborates public health harm caused by *anything* that discourages access to healthcare – referring to the DHSC's Charging regime - was the advice of the Chief Medical Officer, Sir Chris Whitty to the DHSC in April 2020:

"As the epidemic continues it will become increasingly important to have accurate information on the cases. **Therefore,** <u>anything</u> that <u>discourages</u> that is a <u>risk</u> <u>to public health</u>. <u>I would encourage that we don't charge for treatment</u> of COVID-19 <u>or treatments that arise as a result of COVID-19</u>."²⁰ (emphasis added)

- 39. The DHSC never acted on this advice. Treatment that arose as a result of Covid-19 i.e. secondary, continued to be liable to charge. It was never exempted.
- 40. No Government witness has explained why this critical advice was ignored nor gave evidence as to its wider impact.

¹⁹ See also MPCAG Rule 9 [at § 14] and [at § 96] on the 2013 PHE response to consultation on DHSC charging in which concern was raised about access barriers and [at § 94] on the DOTW report evidencing the deterrent effect of the NHS charging regime: Deterrence, delay and distress: the impact of charging in NHS hospitals on migrants in vulnerable circumstances.

²⁰ INQ000068816 – Email from Chris Whitty to the DHSC dated 14 April 2020.

- 41. MPCAG was not granted permission to ask Matt Hancock, the then Secretary of State for Health and Social Care, a direct question about this, nor was this covered by CTI.²¹ MPCAG were similarly refused permission to ask Sir Chris Whitty about his advice and why it was not followed, and CTI did not address it with him.²²
- 42. MPCAG's request for disclosure of the correspondence surrounding Sir Whitty's email advice to the DHSC was refused by the Inquiry on the basis that *"these issues are not sufficiently relevant to the issues under investigation in Module 4" (our emphasis).* MPCAG expresses serious concern regarding the suggestion that such DHSC's policies on healthcare access are in anyway irrelevant.
- 43. <u>Third</u>, even where the exemption applied, and was understood by the migrant to apply, migrants seeking treatment remain at risk of erroneous charges nonetheless being applied by the NHS due to misunderstanding of the complex Regulations. This well documented problem fuels the wider fear and mistrust experienced by migrants when accessing healthcare services.
- 44. Illustrative of this precise point are the reports received by MPCAG from migrants of wrongful charging for COVID-19 treatment. Anna Miller stated unequivocally in her evidence to the Inquiry "*I've even seen an NHS trust pursue charges for a [Covid] vaccine*."²³
- 45. The sheer force of the deterrent effect created by the DHSC's Charging regime could not be solved by the simple introduction of the January 2020 exemption hidden in an Annex to the Regulations. Regardless of how well this exemption was communicated this would, in and of itself, be insufficient to engender real trust amongst migrants to access the vaccine and therapeutics so long as the wider Charging Regime remained operational.

²¹ Proposed Rule 10 Questions for Matt Hancock from MPCAG: "*Professor Sir Chris Whitty advised that the charging regulations be amended removing charges secondary and pre-existing conditions, cautioning not doing so could be a risk to public health. Q: What consideration did you give to this advice? Q: What consideration was otherwise given to the DHSC policy of NHS Charging during the pandemic? Q: This advice was not followed. Why was this advice not followed? What did you consider the impacts of not following this advice would be? ".*

²² Proposed rule 10 questions for Sir Chris Whitty MPCAG: "On 4 April 2020, an official at DHSC based at Visitor and Migrant NHS Cost-Recovery Programme sought advice from you on NHS Charging regulations, in particular whether pre-existing and secondary conditions should become exempt as a result of Covid-19. ...Your office confirmed that this advice related to pre-existing and secondary conditions that required treatment at the same time as Covid-19. Q: Please expand on your advice that continuing NHS charging for pre-existing and secondary conditions would create a 'risk to public health.' Q: This advice was not followed by DHSC. What in your view, was the likely impact of the decision not to revoke or suspend NHS Charging regulations in relation to secondary and pre-existing conditions"

²³ Transcript of 15 January 2025 [104/19].

Moreover, the evidence shows that NHS trusts themselves erroneously charged individuals.

46. Logically, in light of this evidence, the only change capable of properly and fully overcoming the deterrence of fear and mistrust, in the public health interests of facilitating access to healthcare for all in a future pandemic, is the permanent discontinuation by the DHSC of the charging regime being applied to all people living in the UK, regardless of immigration status. It is only abolition of this regime that will quell well-founded fears about mischarging and remove the risk of erroneous charges. This action will contribute to the gradual but critical restoration of trust between migrants and healthcare services.

Data sharing practices between the Home Office and NHS

- 47. Allied to this it is the data sharing practices between the DHSC and the Home Office which are set out extensively in MPCAG's Rule 9 [at § 110 120].
- 48. The key points to note are:
 - i. Regulation 3A of the DHSC's Charging Regulations *requires* NHS bodies to record the immigration and charging status of patients.
 - ii. The DHSC's 'Guidance Immigration status checks by the NHS: guidance for overseas patients' *empowers* NHS Trusts to undertake immigration checks on patients by contacting the Home Office to request information on an individual's immigration status to *determine* exemption from the charging regime. Thus, the NHS become the enforcers of that entitlement to free access or denial (i.e. charging), rather than the department charged with immigration control, i.e. the Home Office.
 - iii. The UK Health Security Agency, 'Guidance: Information sharing with the Home Office for unpaid NHS debts: privacy notice' *requires* NHS Trusts to inform the Home Office of any unpaid debt owed by an overseas visitor.
 - iv. The DHSC's 'NHS Cost Recovering overseas visitors' guidance' mandates NHS Trusts to report to the Home Office the personal details of any patient with a debt of more than £500 that has been outstanding for more than 2 months with no payment plan in place.
- 49. All these provisions remained fully operational throughout the pandemic.
- 50. No firewall or mechanism was ever implemented to stop data-sharing practices during the pandemic.

- 51. No other patient group, other than migrants, are subject to their data routinely being shared by the DHSC for non-clinical purposes.
- 52. To assist the Inquiry in understanding the severity of this practice, Miss Miller explained that based on her insight from the Médecins du Monde network running clinics all across Europe, "The UK is an outlier in terms of the extent to which people are charged and punished for accessing NHS services and this very interconnected way in which health data is used to support immigration enforcement. It's really important to not view that as an immigration policy, and also not to view that as an essential or even a normal part of a healthcare system".²⁴
- 53. It is unsurprising therefore that the sharing of personal data between the NHS and the Home Office has triggered deeply entrenched fear and mistrust within migrant communities towards healthcare services, who are viewed as an extension of Home Office immigration enforcement powers.
- 54. The consequences of data-sharing practices were compellingly identified by the Inquiry's own expert:

"Data sharing arrangements mean that the NHS is legally obliged to inform the Home Office if there is unpaid debt for NHS hospital treatment, which may be a ground to refuse an application for a new visa, or extension of stay for a person subject to immigration control (Department of Health & Social Care, 2019; UK Health Security Agency, 2019). As part of determining a person's eligibility for care, NHS Trusts can seek information from the Home Office about an individual's immigration status and share the patients' personal details (e.g. address). This can result in a fear of immigration enforcement. Evidence indicates that this framework does not only affect people with insecure immigration status, but raises implications for migrants and people from minority ethnic communities (who hold residency rights and citizenship) who have been subject to racial profiling in NHS settings. For example, UK citizens from ethnic minority backgrounds being asked to prove eligibility to receive NHS care without charge in England (Institute for Public Policy Research, 2021; New Economics Foundation, 2020). The impact on vaccine decisionmaking among such population groups during the Covid-19 pandemic needs to be understood, and lessons for preparedness learnt accordingly. Deal et al (2021) note that the UK Government announced that people with insecure immigration status could register with a GP to receive a Covid-19

²⁴ Transcript of 16 January 2025 [112/1] – [112/11].

vaccine without facing immigration control checks in February 2021, <u>but</u> <u>no statements were made about whether registration would entail data</u> <u>sharing with the Home Office or immigration enforcement in the future</u>. Moreover, participants in this study were not aware of the UK Government announcement. Such lack of clarity, and ineffective communication pathways, is not conducive to building confidence in pandemic vaccine offers for people with insecure immigration status." (emphasis added) [Kasstan-Dabush at § 268] (our emphasis)

- 55. The clearly identifiable fear cultivated by the DHSC's data sharing practices were simply not addressed as a fundamental barrier to access for vaccines and therapeutics for migrants.
- 56. At no stage did the Government give a clear and unqualified guarantee that accessing the vaccine or therapeutics would not result in any information being shared with the Home Office. This is because, absent a data firewall, no such guarantee *could* have been given:
 - i. The Government's brief to the Daily Mail in February 2021, who ran a front cover entitled "Vaccine amnesty for migrants" was misleading. This promised that no action would be taken by the Home Office for migrants accessing the vaccine. It was **not** a promise that data would not be shared with the Home Office.
 - Government messaging was later refined to state "no immigration checks are needed for overseas visitors if they are only tested, treated or vaccinated."²⁵ Again, this was not a promise that data would not be shared with the Home Office.
- 57. Such a guarantee would *only* have been possible if the DHSC had suspended mandatory data-sharing provisions under the Charging Regulations and its guidance. <u>This did not happen.</u>
- 58. It is paramount that universal patient confidentiality and data security within the healthcare system is a guarantee for all. This can and should be done now, without prevarication.
- 59. Anything less than a permanent end to data sharing practices would be insufficient to rebuild the bond of trust that has been broken between the NHS and migrants.

Barriers to GP registration and NHS numbers

60. Chronically low levels of registration with GPs amongst all section of the migrant population was well evidenced and known by Government before the pandemic. This begs

²⁵ COVID-19: migrant health guide, Advice and guidance for healthcare practitioners on the health needs of migrant patients.

the question why more was not done, particularly in the initial stages of the vaccine rollout, to remove this practical barrier that would invariably be experienced by affected migrants (and other vulnerable Inclusion Health Groups) through simply not being able to book a vaccine appointment via the National Booking System.

- 61. As Anna Miller stated in her oral evidence: "once we realised the vaccine the main way people were going to access to the vaccine was through the national booking system, and that you had to have an NHS number to be able to use the national booking system, we became aware that our patients were going to be completely excluded from the vaccine rollout."²⁶
- 62. The British Medical Association in their opening submissions confirmed that "not having an NHS number became a barrier to vaccine uptake for many people in the homeless population, as well as for vulnerable migrants. Despite there being no need for a fixed address to access the vaccine, there were reports that some people still faced this barrier."²⁷
- 63. Yet the universal vaccine rollout model adopted, without any adaptations for those it would exclude, was first for GPs to identify from within their records individuals eligible for early vaccine, and second for individuals to book a vaccine appointment through the National Booking System that required an NHS number that migrants can *only* obtain through GP registration.
- 64. GP practices routinely and wrongly refuse to register migrants who lack documentation, proof of address or immigration status, in flagrant breach of NHS England guidance. This must be remedied, and internal and cross-departmental policy communication made more effective²⁸.
- 65. Simultaneously, it is imperative for the Government to acknowledge that the insidious deterrent effect of the DHSC's Charging regime and data sharing practices leaches into access to primary healthcare. Whilst primary healthcare is free, if migrants are continuously subjected to fear and mistrust of charges and data sharing they can and will associate this with *all healthcare services* regardless of the distinction in law between primary and secondary services.

Failure to build trust and refusal to remove barriers

²⁶ Transcript of 15 January 2025 [106/17-23]. NB - The reference to patients are DOTW patients who are all migrants or children born to migrant parents.

²⁷INQ000474789 [at §54 (b)].

²⁸ See MPCAG Rule 9 at §§134-147.

- 66. As a result of the Government, particularly the DHSC, failing to prioritise healthcare over immigration policy, and thereby failing to build critical trust amongst migrants, any peripheral efforts undertaken were inadequate and ineffective.
- 67. Whilst the Inquiry has heard evidence of inadequate and belated Government efforts to communicate policies intended to mitigate barriers faced by migrants, it is vital to underscore MPCAG's position: Embedded structural deterrents to vaccine uptake simply cannot be overcome by communications strategy. Message cannot remedy substance. It would therefore be misguided for the Inquiry to conclude that low migrant vaccine uptake could have been remedied by improved communications. This would be tantamount to addressing only superficial level barriers without scratching below the surface to address the root cause.
- 68. This essential point notwithstanding, the Government's communication strategy was woefully inadequate. As Anna Miller observed in her evidence to the Inquiry, "*it wasn't until then [February 2021 that] the Government briefed the Daily Mail, and then a little bit later the BBC, and that was pretty much the extent of it. …Those are not places where migrants in the UK tend to get their information from. So that was the extent of it."²⁹*
- 69. It is important to acknowledge that the *Daily Mail* is well-known for regularly publishing anti-migrant rhetoric. The Government's decision to prioritise this publication as the primary vehicle for migrant-specific messaging premised on the flawed assumption that migrants engage with a newspaper that routinely vilifies them reflects a striking degree of ignorance and misjudgement. This choice fundamentally undermines any claim that the Government's communication strategy was either effective or thoughtfully devised.
- 70. In addition, the Government failed to translate information about COVID-19 vaccine entitlement in a timely and comprehensive manner, leaving many migrants without accessible guidance on their rights to vaccination. This failure not only hindered equitable vaccine access but also reinforced barriers of exclusion and mistrust among migrant communities. In contrast, DOTW played a far more proactive role, undertaking the bulk of translation work to ensure migrants could access accurate information.

V. CONCLUSION: LESSONS LEARNED AND RECOMMENDATIONS

71. Trust cannot be rebuilt, or fear dispelled, in a day. Without the assurance that healthcare interactions are free from the risk of immigration enforcement, many migrants—already

²⁹ Transcript of 15 January 2025 [98/10] – [98/17].

vulnerable due to socioeconomic and legal precarity — are likely to continue to avoid seeking healthcare, resulting in preventable suffering and unnecessary deaths.

- 72. The prioritisation of health over immigration policy must be regarded as a fundamental principle for any effective pandemic and public health response. Unqualified action, not merely words, in implementing this prioritisation would begin to restore the broken trust in healthcare systems. It would safeguard the dignity and safety of all individuals and ensure that public health measures are both equitable and effective.
- 73. Such reforms would not only benefit migrants but would yield broader societal gains, strengthening the UK's capacity to respond to a future pandemic.
- 74. Throughout the Inquiry many government bodies and various CPs made the point that enhanced data collection could offer an effective solution to issues and barriers that have been identified. MPCAG wish to express a note of caution in this regard.
- 75. As far as MPCAG are concerned, *this* Inquiry has received sufficient evidence to be able to identify the root causes of the issues that affect migrants and to make recommendations that will *directly* address and seek to remedy these problems. More data collection would simply amount to collecting more evidence of the problem, without remedying the *cause* of the problem.
- 76. Whilst increased data collection may present a potential solution for addressing the needs of *certain* marginalised groups, it is far from a suitable panacea. As is clear from the powerful deterrent effect of the DHSC's charging regime, arising from increased checks on an individual's immigration status, expanding the demands of data recording for individuals can have unintended consequences such as racial profiling, discrimination and breeding a culture of mistrust.
- 77. Sir Chris Whitty correctly identified the counter argument for increased data collection and data sharing: "...people are very nervous about their data being shared for reasons that they don't know and don't agree with. And you do have to get that balance right. You have to both be able to absolutely guarantee the security of the data but you also have to make sure that this is being used for purposes that people would want it to be used for". ³⁰
- 78. Unless proper and absolute measures are implemented to secure and protect personal data from being shared for punitive and non-clinical reasons, and *unless* there is sufficient trust in these protective measures, the result of increased data collection for migrants could be devastating in exacerbating the healthcare barriers they already experience.

³⁰ Transcript for 20 January 2025 [54/1] – [54/7].

- 79. Early and meaningful engagement with migrant organisations is essential. Groups like MPCAG *already* hold the evidence and data the Government needs. They played a crucial role during the pandemic, stepping in where Government policies failed to meet migrants' needs. Despite limited resources, they bridged gaps and implemented practical solutions overlooked by policymakers. However, their efforts can only go so far while structural and exclusionary policies continue to deter migrants from accessing vital healthcare.
- 80. On this basis, MPCAG invites the Chair to adopt the following recommendations in her final report on Module 4:
 - i. Public health policy must always, and in practice, be prioritised over immigration policy.
 - ii. The DHSC's charging regime must, without delay, be permanently discontinued or repealed.
 - iii. There must be a permanent data-sharing firewall between healthcare services and the Home Office, especially if there is to be increased focus on health data collection. This would not prevent the DHSC from seeking to enforce their charging regime, but it would allow for patient confidentiality when seeking access to healthcare and treatment.
 - iv. In addition to the Covid-19 charging exemption being made and properly communicated as to its terms, a clear and legally enforceable firewall against such data sharing and one that was understood by all NHS trusts was required during the pandemic.
 - v. GP surgeries, hospitals, and vaccine centres must be designated as 'safe spaces' where immigration enforcement action is prohibited.
 - vi. All barriers to accessing primary healthcare and registering with a GP must be removed. The Home Office must amend its Statement of Requirements with Asylum Accommodation providers to ensure that support is provided to all residents to register with a GP within the first 5 days.
- 81. Each of these recommendations addresses specific Government failings during the pandemic. They are supported not only by MPCAG's frontline experience during the pandemic and years of expertise in supporting migrants to access healthcare, but by the evidence of other CPs and, critically, the Inquiry's own experts.
- 82. The need for such clear and robust recommendations is increasingly urgent. Past efforts and recommendations have gone unheeded. For this Inquiry to have been effective, now is the time that lessons really must be learned and real change achieved.

- 83. Public health policies should be anchored in humanity and consistent with the importance of maintaining public health in its broadest sense. The Government's failures exposed by the Covid-19 pandemic were not mere oversights but the result of a systemic entanglement of healthcare and immigration enforcement, an approach that has repeatedly marginalised migrants in public health policy and access to primary healthcare. The recommendations outlined above are the bare minimum necessary to ensure no one is excluded from life-saving healthcare due to fear, data-sharing, or bureaucratic barriers.
- 84. The recent House of Lords Statutory Inquiries Committee³¹ warns that poor implementation of recommendations has undermined public inquiries, reducing their effectiveness, damaging their credibility, and increasing the risk of repeated disasters while failing to reassure victims. This Inquiry offers a crucial chance to end this cycle within the clear framework of the Terms of Reference and Scope for this module and to serve central the purpose of any Inquiry, let alone the biggest public inquiry ever held in the UK.
- 85. A future pandemic has been described as a "racing certainty."³² The Inquiry must therefore act urgently and decisively. Any recommendations for pandemic preparedness must prioritise public health over immigration status and guarantee healthcare access <u>for all</u>, regardless of immigration status.

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Garden Court Chambers

14 February 2025

³¹ Public Inquiries Enhancing Public Trust, 16 September 2024.

³² Sir Jonathan Van-Tam in his oral evidence to the Inquiry. Transcript of 20 January 2025 [136/25].