IN THE UK COVID-19 INQUIRY - MODULE 4

OPENING WRITTEN SUBMISSIONS ON BEHALF OF THE TRAVELLER MOVEMENT

Introduction

1. The Traveller Movement (**'TM'**) is a registered charity and the largest representative body engaging with national and local government for and on behalf of Gypsy, Roma and Traveller (hereafter **'GRT'**) communities in the UK. It was designated as a core participant on 17 July 2023 in module 4 of the Covid-19 Inquiry.

2. The GRT population has been estimated at approximately 300,000 of the UK population (although the true number is likely to be greater as there are 'data capture' issues surrounding the recording of GRT ethnicity in institutions such as NHS). It is likely that the GRT communities account for between 0.5 and 1% of the UK population.

3. Module 4 is important to the GRT population because these communities were largely ignored in the Covid-19 vaccine rollout programme. It is a matter of considerable concern that GRT faced higher risks of hospitalisation and death through Covid-19.[1] They also faced enhanced risks and higher mortality rates[2]. Furthermore, the evidence before the Inquiry demonstrates that GRT experienced the lowest vaccine uptake of any group during the Covid-19 pandemic[3].

4. TM's primary concern is that the Inquiry makes sufficiently robust findings and recommendations in this module to ensure that if another pandemic were to occur in

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[1] Research undertaken at the University of Glasgow in 2023 has confirmed that GRT faced higher risks of hospitalisation and death through Covid-19 when compared to white Scottish groups.
[2] See - Article by Matthew Bosworth et al – Ethnic differences in COVID-19 mortality in the second and third waves of the pandemic in England during the vaccine rollout: a retrospective, population-based cohort study, dated 2023.
[3] See paragraph 5 below

the future, the government and medical agencies will be better placed than in 2020/21 to ensure that GRT receive adequate information about vaccines and that discrete and major barriers to vaccine uptake GRT experience are addressed.

GRT were the highest unvaccinated group within the UK population

5. The Inquiry's own experts Dr Ben Kassan-Dabush and Dr Tracey Chantler confirm at paragraph 184 of their November 2024 report that GRT (in Scotland) were a third as likely to take up one or more vaccine doses compared with the white Scottish population (Public Health Scotland, October 2022).

6. Furthermore, paragraph 184 of the report contains a table showing GRT as the highest unvaccinated group within the population at 55.1% unvaccinated. This is the only group in which over half of its population did not receive COVID vaccines. It is important that the Inquiry investigates the reasons behind this stark fact.

7. TM's position is that many institutions simply had no visibility of the position of GRT (or indeed other marginalised communities) during the Covid-19 vaccination programme. Remarkably there is no mention of GRT by the National Audit Office in its comprehensive report dated 25 February 2002 entitled: *The rollout of the Covid-19 vaccination programme in England*. The Inquiry will no doubt wish to consider why this group, which experienced among the worst outcomes, was ignored in this and other reports.

8. TM is anxious to impress upon the Chair that it is imperative that the Inquiry addresses the position of GRT in relation to the vaccination programme within Module 4, if it is to fulfil its Terms of Reference. Paragraph (a) of the Inquiry Terms of Reference refers to the need 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 and equality categories under the Northern Ireland Act 1998. Furthermore, paragraph 2 of the TORs required the Inquiry

to identify lessons to be learned, to inform preparations for future pandemics across the UK.

GRT were the least likely group to have received at least one vaccine dose

9. The evidence disclosed to core participants within this module of the Inquiry (thus far) supports the understanding and experiences of TM in relation to the position of GRT during the pandemic.

10. In particular, a document from Public Health Scotland dated 29 June 2022 entitled *'Learning from the flu and Covid-19 vaccination programme evaluation'* reveals that most minority ethnic subgroups had a decreased likelihood of vaccine uptake compared with the white Scottish ethnicity group. However, when measured against 15 other minority groups the Gypsy / Traveller communities had the lowest rating of all, and were shown to be the least likely to have received at least one vaccine dose.

GRT vaccine hesitancy and low uptake issues were known about prior to the pandemic.

11. The authors of the Public Health Scotland study referred to research that had been undertaken and cited a January 2018 (over 2 years before the March 2020 lockdown) European Journal of Public Health review, which had found that there were barriers to healthcare services for GRT including organisation of health systems, discrimination, culture and language, health literacy, service user attributes and economic barriers.

12. Further reference was made to a qualitative exploration of barriers to immunisation in GRT groups undertaken by the BMC Public Health journal dated March 2017 (3 years before the March 2020 lockdown). This study suggested discrimination, low literacy, hesitancy at combined vaccinations, poor school attendance, poverty and housing as being prevalent impediments to vaccinations within this group.

13. The Public Health Scotland evidence is therefore important to the Inquiry for two reasons:

- First, it shows, from a regression modelling perspective, that GRT had the lowest vaccine uptake of any social group in Scotland.
- Second, it shows that in the 2 years before the pandemic, GRT had been flagged, by two reputable research organisations, as a group that was particularly vulnerable to vaccine hesitancy and low vaccine uptake. These were matters which the institutions concerned with vaccine rollout knew about or ought reasonably to have known about.

Anticipated Rule 10 questions

14. TM (and the GRT community it represents) wish to know why the GRT communities were largely ignored in relation to the vaccination programme. The evidence detailed above gives rise to a number of questions which TM say the Inquiry should consider, and which we will put to Inquiry witnesses through the Rule 10 process. These questions include:

(i) What steps were taken by government and healthcare institutions to identify the size and location of the GRT population?

(ii) What steps were taken by government and healthcare institutions to understand the position of GRT prior to the implementation of the vaccination programme?

(iii) What, if any, actions were taken to address the impact of a vaccination programme on a community which suffers discrimination and marginalisation?

(iv) Who, if anybody, was charged with addressing potential vaccine hesitancy or low uptake in relation to this group?

(v) What actions were taken by government and healthcare institutions to guard, against vaccine hesitancy or low uptake in relation to this group?

(vi) What, if any, consideration was given to appropriate specific or tailored dialogue with GRT communities?

(vii) Which individuals, departments or institutions were responsible for failing to ensure that GRT hesitancy and uptake issues were addressed during the rollout programme?

(viii) If there were to be a future pandemic, how would issues relating to GRT vaccine hesitancy and uptake be addressed? What would be done differently?

Failure to establish trusting relationships

15. The Covid-19 vaccination programme was rolled out on 8 December 2020. In July of that year the Journal of Public Health published an article entitled*: Improving immunization uptake rates among Gypsies, Roma and Travellers: a qualitative study of the views of service providers*. The authors of that article noted that GRT are known to be at risk of low uptake of immunisations and that Travellers are generally considered to have poorer health than the general population and when compared to disadvantaged groups.

16. In particular, the report notes that health system contributing factors to low GRT uptake include: discrimination against Travellers leading to lack of trust in health providers, reluctance to register Travellers by GP practices and a failure to routinely collect ethnicity data during NHS care.

17. Furthermore, the report notes that within Traveller communities language and literacy difficulties, insufficient knowledge of health systems, poverty and beliefs about self-reliance are perceived by Travellers and service providers as barriers to accessing services.

18. Research was undertaken in four UK cities where 6 Traveller communities were based (Bristol, Glasgow London and York). Thirty-nine service providers **('SPs')** were interviewed and four major themes emerged from the evidence that had been gathered.

19. First, SPs in all cities spoke about the importance of building trusting relationships with Traveller families and need to understand community concerns regarding specific vaccines. SPs described ways to support the development of trusting relationships. These included continuity of services and individual care providers and face to face engagement. Also, specialist health visitors for Travellers were highly valued in all four cities for their strong relationships with families and knowledge of Traveller culture.

20. Second, SPs reported that many Traveller families were not registered with a GP. Traveller culture was described by some service providers as being responsive to health need rather than proactive. Having a large family with many children often increased difficulties of booking or attending appointments and these factors led to lack of uptake of immunisation appointments.

21. Third, concerns were raised by SPs in relation to the lack of routine data collection on Traveller ethnicity - such as GP practices not recording Traveller ethnicity at registration, and the child health information system not including this information. Currently NHS systems do not include a GRT ethnic category for staff to complete. This has led to a lack of understanding between SPs and local Traveller communities.

22. Fourth, the 2013 NHS reforms in England, which resulted in responsibility for health protection and immunisation programmes being moved to Public Health England (then a new organisation) were regarded as having had a negative impact on the ability of SPs to improve uptake of immunisations in Traveller communities. Consequences of the reforms included loss of organisational memory and designated authority for action, across both health and partner services. These changes led to a perception that healthcare teams had shifted from proactive to reactive provision.

23. Furthermore, the 2013 changes led to reduced funding for awareness campaigns or staff training and created a situation whereby specialist health visitor posts where sometimes no longer available.

24. The research demonstrates that trust is a prerequisite to delivering effective services and thus specialist health visitors for GRT had the potential to counter the impact of vaccine hesitancy.

25. Along with the decline of specialist health visitors the absence of high quality data describing family ethnic groups was a significant barrier to monitoring inequalities in uptake and the impact of targeted activities.

26. We submit that the outcome of the JPH research demonstrates that (1) culturally aware health visitors for GRT and (2) effective data capture systems are vital prerequisites for any future pandemic to guard against low vaccine uptake in the GRT communities.[4]

Failure to establish community-based vaccination hubs

27. In addition to the need to retain specialist health visitors, any future vaccination programme should take account of GRT issues through provision of tailored or bespoke facilities. A Public Health Scotland document dated September 2021, entitled *Learning from the interviews with Health Board vaccination leads about their experience of the COVID-19 vaccination programme* suggests that many minorities might have found the mass vaccination process overwhelming and puts forward the following targeted responses to GRT vaccine hesitancy :

(i) Individual community-based vaccination hubs, such as drop- in mobile or pop- up vaccination clinics for particular groups, rather than central hubs for the entire community.

(ii) Specific work with GRT leaders who were *'well thought of and had a positive influence on the communities'* to provide understanding.

[4] We note that Dr Ben Kassan-Dabush and Dr Tracey Chantler highlight the issue of data capture at paragraph 186 of their November 2024 report

28. TM maintains that the lack of individually tailored, and culturally sensitive facilities contributed to the inadequacy of the vaccine rollout programme insofar as it related to the GRT communities. The conclusions set out in the JPH and Public Health Scotland reports detailed above were not innovative and ought to have been obvious to those institutions which administered the Covid-19 vaccination programme. We will put these issues to appropriate witnesses through the Rule 10 process in this module of the Inquiry.

Discrimination and lack of trust – underlying reasons for vaccine hesitancy.

29. TM takes the view that it is not possible to separate the discrimination and marginalisation that GRT suffer from the vaccine hesitancy and attendant low uptake of Covid -19 vaccines within the communities.

30. We ask that the Inquiry considers an article in Vaccine Journal by Charlotte Kuhlbrandt et al dated June 2023 and entitled *Covid-19 Vaccination decisions among Gypsy Roma and Traveller communities: A qualitative study moving beyond vaccine hesitancy.* This article challenges the received wisdom that the best way to increase uptake of vaccination is via interventions that focus mainly on informing and educating populations about vaccines.

31. The reality is that amongst marginalised minority groups the social and historical contexts in which people make decisions about vaccinations will always be crucial. TM maintain that this crucial factor was missed or misunderstood by government and medical institutions in relation to GRT and Covid-19 vaccine rollout.

32. TM agrees with Kuhlbrandt et al that GRT low vaccine uptake was intrinsically linked with social marginalisation and exclusion. Historically, those with nomadic lifestyles tend to be made to feel unwelcome by the general population. The Caravan Sites Act 1968 attempted to address this issue through requiring local authorities to provide authorised sites to GRT, who were experiencing routine evictions caused by

enclosures of common land. However, in practice around 10,000 GRT members are forced to live on unauthorised sites because of failure by local authorities to meet their spatial planning duties. Such people were unable to register with GPs or access the vaccine programme through the medical authorities.

33. These problems have been compounded by Police, Crime, Sentencing and Courts Act 2022, which criminalised trespass and is seen by the GRT communities as a statutory impediment to nomadic living and a means of exacerbating inequalities through driving ever more GRT into the criminal justice system. [5]

34. It is relevant to note that Parliament debated and passed this Act (then in Bill form) during 2021 to 2022 at the same time as the COVID-19 vaccination rollout. Accordingly, the GRT communities felt under attack at the time of the vaccine rollout. In addition to the proposed legislation, vaccine status was also seen by GRT communities at this time as means of restricting traditional travelling lifestyles.

35. Many GRT community members believe that they were abandoned during the pandemic. There are numerous examples of inappropriate treatment of GRT by the authorities at that time. The Kuhlbrandt et al report refers to Travellers having to attend Accident and Emergency Departments after failing to obtain appointments for general practitioners because of delays getting appointments.

36. The report also details the stark experience of a woman who lived on a council Traveller site, who stated that no health visitors came to check up on her newborn baby who was losing weight. She was told by health staff to weigh the baby herself and left the site to buy scales worrying that she would be reprimanded for breaking lockdown rules.

37. Other GRT members related experiences of problems with ambulances being unable to drive onto designated Traveller sites to provide urgent treatment. In some cases

[5] It is notable that 12% of children in STCs and 7% in YOIs identified as Gypsy, Roma or Traveller.https://committees.parliament.uk/writtenevidence/105542/pdf/#:~:text=12%25%20of%20children%20in%20STCs,as%20Gypsy%2C%20Roma%20or%20Traveller.

ambulances were unable to enter sites because councils had installed high metal barriers at the entrance to prevent Travellers moving caravans onto the sites. In other examples, postmen told Travellers that they would not deliver to sites because they had been told that they would not be insured.

38. It is easy to see how such incidents engendered high levels of mistrust within GRT communities. Those GRT who did receive vaccines often did so because they felt coerced. Many others did not receive vaccines because they held misconceptions about the vaccines themselves, which were not addressed by the authorities. Some women had concerns that vaccines would cause infertility, notwithstanding the presence of information online that should have disabused them of these concerns. Other members of the communities considered that if they were generally healthy, they did not need to receive vaccines.

39. Sufficient steps were not taken to address rumours and concerns held by GRT about vaccines. However, the mere provision of information is not the answer to low uptakes of vaccine within minority communities, if authorities do not take pro-active steps to cultivate trust within marginalised and discriminated groups. The Kuhlbrandt et al study supports the view that the key failure which led to increased vaccine hesitancy and low uptake was lack of personalised engagement with communities in ways that respect and address local and culturally specific concerns.

40. The report concludes that community engagement with GRT cannot be effective if conducted in a 'top down' fashion. There needs to be a two-way dialogue if trust issues are to be resolved. Ultimately, the fundamental problem with the vaccine rollout for GRT was that the authorities disregarded the underlying day to day discrimination which GRT face and which is causative of the trust issues.

41. We will address the failure by institutions to address the underlying discrimination issues and lack of trust in authorities during the Inquiry module through our submissions and through the Rule 10 process. These matters were at the heart of the high levels of vaccine hesitancy within the GRT communities.

Successful 'pre-pandemic' vaccinations programmes for GRT.

42. The Inquiry is referred to a report dated 25 May 2021 from the Public Health Agency Health Intelligence Unit. *Resource pack- COVID-19 vaccination in marginalised and vulnerable communities.*

43. Importantly, this report confirms that there have been successful vaccination programmes in the past which were directed towards or included a substantial proportion of GRT people. These programmes have included measles vaccination and postpartum influenza vaccination. In those cases vaccine hesitancy or refusal did not seem to be a significant barrier to uptake.

44. The report states that successful programmes used mobile vaccination clinics that were geographically located within or near to GRT settlements. Although there were concerns that this could further distance GRT users from the mainstream healthcare system, these services are best seen as a pathway to accessing mainstream services, rather than providing an alternative service entirely. The report stresses the importance of involving GRT representatives in the design of effective interventions.

45. This type of bespoke and community targeted dialogue seems to have been absent within the vaccination programme during the COVID-19 pandemic. TM are understandably frustrated that they and other GRT charities were not utilised as a conduit between authorities and communities. We will ask institutional witnesses why the means by which successful vaccination programmes for GRT had been implemented in the past were seemingly disregarded in 2020 and 2021.

Digital Exclusion

46. Another relevant factor to GRT vaccine hesitancy and low uptake is digital exclusion. TM maintains that only 1 in 5 GRT members have access to the internet and that consequently many people in these communities were unable to follow any guidance or directions relating to vaccination. Publishing guidance online and requiring that

appointments are booked online excludes those without digital access or digital literacy.

47. A report from Doctors of the World UK entitled *A Rapid Needs Assessment of Excluded People in England During the 2020 COVID-19 Pandemic (May 2020)* stated that *'as well as limiting ability to follow the guidance, this deepens actual and perceived exclusion from this information. Interviewees reported that many are instead using their family and peer networks to share this information.'* Doctors of the World UK quote from a Manager of the Southwark Travellers Action Group, who stated: *"I am really aware a lot of people we are trying to get in contact with are older and vulnerable and don't have computers, and they won't see Facebook. It's very difficult to know how to get information out to them".*

Literacy issues

48. Poor literacy within the GRT communities was another impediment to vaccination. The Doctors of the World UK report goes on to state: *People from Gypsy, Roma and Traveller communities and people experiencing homelessness often have lower levels of literacy than the general population, so many cannot access written guidance..... We heard an example where GPs were sending letters to people informing them they were clinically extremely vulnerable to COVID-19, despite these people being recorded as without literacy on the GP system. Those without the social support structures to help them understand the guidance have therefore been excluded from this information.*

49. TM maintains that the vaccine rollout failed to take account of digital exclusion and literacy issues in the GRT communities. Those administering the Covid-19 vaccination programme knew about these matters or ought reasonably to have known about them.

Lack of data capture

50. As stated above, it is estimated that the GRT population in the UK is approximately 300,000. A University of Salford study in 2013 estimated a Roma population of 200,000 and a Gypsy and Traveller population of 200,000 to 300,000. This accounts for between 0.5 and 1% of the population. However, the true size of the communities is unknown. This is partly because ethnicity data for GRT is neither accounted for in NHS records, nor appropriately recorded in the national census.

51. The 2011 census revealed that 58,000 respondents identified as being of Gypsy or Irish Traveller, with a further 4000 in Scotland. This was the first time that any census had requested details of Gypsy and Traveller ethnicity. However, the census did not provide for identification of those with Roma ethnicity. The Government has acknowledged that the 2011 census was likely to have been an undercount.[6]

52. A consequence of GRT communities not being accounted for in NHS records is that vaccination estimates for these communities are not available within any NHS systems. This is clearly an unacceptable outcome considering what is known about the very low GRT Covid-19 uptake and the numerous health inequalities from which these communities suffer.[7]

Issues with GP surgeries and ambulances

53. A survey conducted by TM in 2017 found that 91% of 199 respondents had experienced discrimination. Sadly, the prevalence of discrimination was present in the treatment of GRT during the pandemic.

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[6] See House of Commons Women and Equalities Committee: Tackling inequalities faced by Gypsy, Roma and Traveller communities. 20 March 2019.

[7] The health status of gypsies and travellers is much poorer than that of the general population. Life expectancy is 10 to 12 years less than those of the non-traveller population. 42% of English gypsies are affected by a long-term condition as opposed to 18% of the general population. One in five traveller mothers will experience the loss of a child compared to one in 100 in the non-traveller community. See HC Women and Equalities Committee Report at paragraph 19.

54. An article in the Independent, dated 8th July 2021 states that GRT community members were refused care by British GP practices during the height of the COVID-19 pandemic. A 'mystery shopping exercise' conducted by Friends Families and Travellers, a charity, disclosed that 74 out of 100 GP surgeries appeared to break NHS England guidance by refusing to register a nomadic patient in March and April of 2021.

55. There are references to refusal to register in the report of Dr Ben Kassan-Dabush and Dr Tracey Chantler at paragraph 262, which states that NHS England regional teams noted that the GRT population was much less likely to be registered at a GP surgery. The experts confirm that GP surgeries are known to refuse registration without proof of a fixed address despite there being no requirement to provide such proof. At paragraph 375 the report states that requiring an NHS number for vaccine scheduling prevents access for those less likely to be registered with a GP service such as people from GRT backgrounds.

Loss of life caused by policing requirements

56. Furthermore, a report entitled *"Access to Health Care for Travelling Communities in the East of England"* Burrows et al September 2021 confirms (at page 8) that lives were lost as a result of discriminatory actions by police, which prevented paramedics reaching GRT people in a timely manner:

> *Serious cases around access to Traveller sites and roadside homes for emergency care were reported. Travelling communities recounted two particular instances where people had died whilst waiting for paramedics to be accompanied by police officers before attending to critically ill patients living on site. It was reported that a man died in Hertfordshire whilst the ambulance was waiting outside the site with a defibrillator. The community were not permitted to take the potentially life-saving defibrillator onto the site.*
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> *In another case, participants reported that a baby died in Thurrock whilst the ambulance was waiting outside for police accompaniment. In this instance, the*

family took their baby to the ambulance but it was too late. In terms of police procedure, it is standard practice in some parts of the East of England for Traveller sites to be flagged in the same way as Drug houses so police must accompany paramedics when attending an emergency.

Conclusions

57. The evidence before the Inquiry (as it stands) demonstrates and confirms TM's position that GRT were largely ignored in the pandemic. Such conduct is particularly egregious because the GRT communities were always at high risk from Covid-19 through an inability to self-distance due to living arrangements.

58. We submit that there is a direct link between lack of trust arising from discrimination and vaccine hesitancy and low uptake. TM maintains that it is no coincidence that one of the most discriminated against groups within society (if not the most discriminated group) had, on the available data, the lowest vaccination uptake of all groups.

59. The Inquiry is asked to make robust findings and recommendations to ensure that the mistakes of the Covid-19 pandemic in relation to vaccination of marginalised and discriminated against communities – especially the GRT communities - are not repeated in any future pandemic or vaccination programme.

60. TM would wish to reiterate that the importance of protecting the GRT communities of the United Kingdom in times of national crisis (and indeed all disadvantaged and marginalised communities) holds a wider importance in ensuring the social integrity and well-being of the United Kingdom at large.

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