## IN THE COVID-19 INQUIRY

#### **MODULE 4 – VACCINES AND THERAPEUTICS**

# CLOSING SUBMISSIONS ON BEHALF OF THE TRAVELLER MOVEMENT

## **Effect of Public Inquiry**

- The Traveller Movement is grateful to the Chair for the opportunity to participate in this
  module of the Inquiry. Public Inquiries are important because they are capable of
  catapulting significant, but perhaps neglected, issues into public consciousness and into
  the minds of institutions, which hitherto failed to act appropriately when needed.
- 2. As a result of its participation in the vaccines and therapeutics module of the Inquiry, the Traveller Movement believes that the sands have shifted, insofar as there is now an institutional understanding and public awareness that Gypsies, Roma and Travellers were largely abandoned in the vaccination programmes and importantly that they were largely statistically invisible and not properly captured, certainly in England, in census records, NHS data and other national data.
- 3. It was uncontentious during the vaccination rollout in December 2020 that the Traveller communities were a health inclusion group by virtue of social exclusion; poor health outcomes and high risk of missing out on vaccination (See paragraph 7.5 of Dr Mary Ramsay's witness statement [INQ000496177\_0033]). Yet it is clear from the limited data that we have and the compelling evidence of Ms MacNamara, the CEO of the Traveller Movement, on 16<sup>th</sup> January 2025, that not enough was done to address the significantly low uptake of vaccines that ensued.

#### No concerted effort at national level

4. The evidence which the Inquiry heard during the three weeks of the Module 4 hearings confirmed that the level of institutional failure towards the three GRT communities was significant. The Chair will recall that Dr Ramsay, the Director of Public Health Programmes at the UK Health Security Agency, stated in her evidence on 21<sup>st</sup> January 2025, in answer to questions from the Traveller Movement, that apart from a single workshop, she was not aware of any concerted effort at national level to ensure the inclusion of GRT and targeting of GRT into the vaccination programme:

Q. ........... We've seen examples, in the evidence, of limited local initiatives to engage the GRT community, for example at Appleby Horse Fair, but we haven't seen in the evidence any concerted effort at a national level to ensure the inclusion of GRT in a systematic manner. And my question for you is, notwithstanding what you've said, but given this lack of data recognition of GRT and the knowledge that GRT faced health inequalities and social exclusion, what specific efforts were made at national level, not locally, but at a national level, to ensure the targeting of GRT communities in the vaccination programmes?

A. I'm personally not aware of specific -- but other than holding that national workshop -- which wasn't about data, that was about trying to make sure the guidance was as facilitative as possible -- I'm not aware of anything specifically at a national level. [6/118/3-20]

#### Most difficult group

5. Furthermore, on 27 January 2025 Kemi Badenoch, the Minister for Equalities at the time of the vaccine rollout, was asked (again by the Traveller Movement) about the lack of targeted initiatives, such as pop-up clinics or bespoke community engagement, in respect of Travellers. She said that it was her understanding that there were GRT based activities, but that of all the groups that the government was trying to reach this was the most difficult group.[9/80/21-24]

6. Ms Badenoch went on to say and that the lack of engagement with Travellers might have been more down to the fact that GRT were difficult to reach, rather than simply because nothing was done. Significantly, she clarified she might be able to explain this, not as a minister, but from her experience as a constituency MP, where she had noted that there was hostility to state bodies.

#### 7. Ms Badenoch stated:

There is a significant level of hostility to any state body, even on the education side -- visiting as a constituency MP, I didn't feel particularly welcome, even though outreach was taking place, and I think that there are many dynamics within GRT, as we've referred to it in government, that make the sort of response we can deliver in a pandemic very, very difficult, especially at short notice. You need people who spend a lot of time, probably of that community, who can do this....[9/81/5-15]

### The impact of discrimination on levels of trust

- 8. The Traveller Movement is keen to impress upon the Inquiry that the underlying reason why some members of the Traveller community appear to be hostile or reluctant to interact with the state lies in the fact that discrimination and marginalisation necessarily breeds distrust and non-cooperation.
- 9. It is imperative that institutions approach the Traveller communities, not from a perspective of bias and negative perception, but with an understanding that the majority of GRT members experience the effects of discrimination on a daily basis and that, as a result of discrimination, they will be naturally suspicious of all institutional messaging, including messaging around vaccines. The Traveller Movement maintains that it is only through properly resourced engagement with the Gypsy, Roma and Traveller communities, and with community leaders, that institutions will be able to create and maintain trust with these marginalised groups.
- 10. There are some areas where the impact of social marginalisation will be greater for GRT, most notably in a number of pockets of chronic exclusion around the UK, such as

unregistered sites, where, as we have stated in our opening submissions, approximately 10,000 Travellers are forced to live as a result of local authorities failing to meet spatial planning requirements.

11. We have provided examples in our opening submissions of discrimination during the pandemic - deaths occurring because ambulances were required to wait for police escorts before entering sites. The particular passage to which we refer is set out at [INQ000474830\_0008] Access to Health Care for Travelling Communities in the East of England. Burrows, S. Green, G. Speed, E. and Thompson, C. September 2021:

"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. 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."

- 12. Travellers also experienced heavy police presences at funerals in circumstances where the number of officers were often greater than the number of mourners. Indeed, many of the problems that the GRT communities faced during the pandemic arose from their perception as a problem for the law enforcement authorities and not as a vulnerable community in need of support and help.
- 13. Furthermore, in several designated council owned sites the local authority installed high metal barriers at the entrance to prevent caravans moving onto the site without permission. These barriers obstructed access to emergency services. See *Covid-19 vaccination decisions among Gypsy, Roma and Traveller Communities: A qualitative study beyond vaccine hesitancy* Charlotte Kühlbrandt, Catherine R McGowan, Rachel Stuart et al-[INQ000474817\_0005].

- 14. There is also evidence before the Inquiry that there were concerns raised during the pandemic that in the UK a significant number of GP surgeries refused to register GRT patients during the Covid-19 pandemic. See [INQ000474813] UK GPs 'refused registration to Gypsy, Roma and Traveller patients' during Covid-19 pandemic, Nadine White, 8<sup>th</sup> July 2021, The Independent: In a "mystery shopping" exercise conducted by Friends, Families and Travellers (FFT) a leading national charity that works on behalf of Gypsies, Roma and Travellers 74 out of 100 of GP surgeries appeared to break NHS England guidance by refusing to register a nomadic patient in March and April [2021] of this year.
- 15. Ms MacNamara provided a stark example of discrimination and institutional failure to understand the position of GRT in her evidence on 16<sup>th</sup> January 2025. She stated:

#### Trust is vital

16. Incidents such as these have significant impacts on the ability of a marginalised community to place trust in the authorities. Later in her evidence Ms MacNamara went on to say:

".....we're not talking about a community that has just arrived on these shores; we're talking about Romani Gypsies in particular who have been on record here for the last 500 years and have been continuously excluded from any kind of provision or service.

So mistrust is going to develop, they're very much persecuted communities, some mistrust is going to kind of develop, and over that time, because there's been no proper outreach programmes, no political will, no gestures of trying to include people in the development of these services, people are incredibly suspicious when something like Covid-19 happens and they're told that they have to get a vaccine, because they haven't had the inclusion, they haven't had the education. So one of the concerns from the community around the vaccine would have been infertility, another one would have been high rates of autism." [3/34-35/18-4].

- 17. The Traveller Movement echoes the position of FEMHO. The Chair will recall the submissions of Professor Thomas KC on 30 January 2025: 'It's about trust' [12/115/2]. Trust is vital. Ms MacNamara emphasised in her evidence the importance of 'building trust with the community before any public health crisis'. [3/37/5].
- 18. The fundamental problem with the authorities' approaches to the GRT communities is that prior to the pandemic only very limited steps were taken to proactively engage to address mistrust and lack of co-operation. So, by the time of the vaccine rollout in December 2020, as Ms MacNamara put it, the flood had already started and it was too late to build the Ark. [3/37/8].
- 19. The process of re-establishing trusting relationships with marginalised communities is essentially a gradual process. Ms MacNamara's view (as detailed above) is that the building of such relationships cannot be left until another pandemic is imminent. The same view was expressed by Dr Chantler in her evidence before the Inquiry on 28<sup>th</sup> January 2025. Dr Chantler stated as follows:

I think what has been lacking in a kind of period of austerity and a lack of funding of public health, is the ability to engage with communities to build those relationships with representative groups of underserved communities so that in this situation, you're not having to suddenly gather people together that do not already work in partnership, but can actually built on existing trusted relationships [10/198/17-25]

#### Mobile health services no longer in existence

- 20. The Traveller Movement considers that the way to generate trust, through effective community engagement, is very much connected and equally important. Ms MacNamara confirmed in her evidence on 16<sup>th</sup> January 2025 that mobile health services for the GRT communities are no longer in existence and that this important outreach should be reinstated because it had been crucial to building relationships with communities.
- 21. Ms MacNamara confirmed in her evidence that the mobile health services allowed people to have someone they could go to with health concerns or issues which fostered a relationship of trust and confidence. She stated these services might have proved very useful when vaccinations were rolled out, because questions about vaccinations would have been dealt with by a health professional who they knew and trusted and in circumstances where Travellers would be more familiar with the healthcare system. [3/26-26/21-5].
- 22. Dr Richardson, the Chief Medical Officer for Wales (at the time of the pandemic) made an important related point in her evidence 28<sup>th</sup> January 2025: (our emphasis)

"I think it's very important for that message to be transmitted by the right messenger. So it's very important to involve trusted voices. So, for particular faith-based communities, or for particular cultural or ethnic minority communities, Gypsy, Roma, Traveller communities, for example, as well, it's essential that the messenger is trusted and so the use of healthcare professionals from those backgrounds, the use of trusted community leaders..." [10/105-106/24-7].

#### Misinformation

23. The Inquiry recall that misinformation was a significant issue for GRT. Ms MacNamara told the Inquiry that rates of child mortality and miscarriages are high in these communities and that rumours spread to the effect that vaccines could lead to infertility or children developing autism. These rumours spread quickly through what is traditionally an oral community and went unchecked. Ms MacNamara stated as follows:

"And we've got to remember that Gypsy, Roma, Traveller communities are traditionally an oral community. So the rumour mill will take hold very, very quickly

and if somebody is saying, "Don't participate in having this vaccine because of, you know, you'll be infertile or your child will end up with autism", or whatever, there is no literature, there is no education programmes to try to counteract at that information, other than what organisations like the Traveller Movement and our colleagues in the sector are trying to do. But we are a drop in the ocean and we are very, very small." [3/35/10-21]

24. It is important to note that a community which suffers from digital exclusion and literacy issues is not only less able to receive vaccine invitations by letter or look at government alerts on the Internet but will also be unable to access government messaging so as to counter misinformation.

#### Lack of effective local interventions

- 25. As stated above, Dr Ramsay's evidence to the Inquiry confirmed that there was a lack of any meaningful initiatives at national level to ensure the inclusion of GRT and targeting of GRT into the vaccination programme. Regrettably it was the case that local interventions were also sparse, particularly in England.
- 26. Aside from local programmes at the Appleby Horse Fair and an initiative in Shropshire involving a TV celebrity, there does not appear to be any evidence that much was done at a local level in England. Witnesses have pointed to the Community Champions Scheme, but the Traveller Movement maintains that this initiative did not address the problem of low vaccine uptake, notwithstanding that local authorities had an awareness of where Traveller sites were located.
- 27. The situation was handled better in Scotland, as Ms Drysdale KC on behalf of the Scottish Ministers set out in her submissions to the Inquiry on 30<sup>th</sup> January 2025. Ms Drysdale KC stated:

"Some key issues that had been raised during this module were recognised and managed in Scotland throughout the vaccine rollout. For example, the Scottish Government worked with trusted partners to alleviate concerns from refugee and asylum seeker communities with tailored messaging. In addition, in Scotland, health boards were asked to put in place outreach for Gypsy, Roma, and Traveller, GRT communities, recognising a high level of historic distrust of authority within these communities. Partnerships were forged with local trusted figures to support engagement, and data was collected on uptake rates for GRT communities when the ethnicity data question was introduced to the Vaccine Management Tool, or VMT." [12/134-135/18-7]

28. We note that Mr Grieve told the Inquiry in his evidence on 28<sup>th</sup> January 2025 that the Scottish Government's approach was to respond to feedback that they received from particular communities [10/54/1-22]. There is also evidence in a February 2022 Scottish Government document entitled: 'Inclusive vaccinations: Phase one of the COVID-19 vaccination programme' [INQ000376293\_011, INQ000376293\_015] that the NHS worked with local authorities and the ambulance services and visited Traveller sites in the Forth Valley and at the Boswell Fair to deliver vaccination.

#### Data

- 29. The issue of data is an important consideration in relation to GRT vaccine uptake. The Traveller Movement's position is that the problems of lack of trust and lack of engagement were compounded by the fact that GRT, who constitute up to 1% of the population, are statistically invisible, particularly in England.
- 30. In her evidence on 16<sup>th</sup> January 2025, Yvonne MacNamara stated that data capture is crucial to vaccine uptake in the GRT communities:

"You know, and the NHS Data Dictionary, NHS Data Model is really, really important. If you're not there, you can't commission services. You can't be part of local planning........ So if you want to develop those local commissioning services and you are serious about addressing health inequality for a community, you have to capture -- you have to know who is in your local community, you have to know your local demographics. And in most of the local authorities I would say there is no local authority in this country that doesn't have a local Gypsy and Traveller community." [3/30/1-17]

- 31. The contrast between the data capture in Scotland and in England is shown at pages 58 and 59 of the Expert Report of Dr Kasstan-Dabush and Dr Chantler [INQ00047623\_0059] and [INQ000474623\_0058].
- 32. At page 59 of the Report Table 18 shows Public Health Scotland data 'Percentage of people vaccinated with at least one dose compared to unvaccinated, by ethnicity in Scotland'. In that table GRT are recorded as the highest unvaccinated group at 55.1% unvaccinated and the least likely group to receive at least one dose.
- 33. Yet on the preceding (page 58) Figure 5 shows equivalent data from England: 'Percentage of adults who received two vaccinations by ethnic group', which fails to refer to GRT at all.
- 34. Dr Chantler and Dr Kasstan-Dabush confirmed at paragraph 95 (page 30) of their report that Public Health England (PHE) 'was aware of limitations in identifying people in underserved or vulnerable cohorts for vaccination, as health care records systems do not routinely record membership of certain 'health inclusion groups'. Consequently, primary care records could not be used to identify and target people in these groups for prioritisation (INQ000496177).'[INQ000474623\_0030]
- 35. It is also noteworthy within the National Audit Office's 21 February 2022 document entitled: 'The rollout of the Covid-19 vaccination programme in England' there is a table at Figure 21 'COVID-19 vaccination uptake by ethnicity, 31 October 2021' [INV000065228\_0063]. This table also omits Gypsy, Roma and Travellers as an ethnic category.
- 36. The point is also raised in the Government's "Final report on progress to address COVID-19 health inequalities" or 'Quarterly Review' (1st December 2021) [INQ000089747]. The report confirms at page 124 that 'Vaccination estimates for Gypsy, Roma and Irish Traveller populations are not available as NHS systems do not have these categories available to choose' [INQ000089747\_0124]. The same report recommends at pages 134 136 [INQ000089747\_0134] that it was a 'high priority next step' to improve ethnicity coding in health datasets inter alia to allow information for GRT groups to presented. Yet it appears that this recommendation has not been implemented.

37. Dame Emily Lawson accepted in her evidence on 27<sup>th</sup> January 2025 that we would not find any figures relating specifically to GRT in the NHSE documentation. Dame Emily's exchange with Mr Keith KC confirms that the authorities in England asked local authorities for information of GRT communities because there was no national data:

Q. And there isn't, we note, any reference here to Gypsy, Roma or Traveller. Would we find figures specifically relating to them specifically anywhere in the NHSE documentation?

A. No, because it wasn't at the time in the -- what's the right word -- the definitions of how ethnicity data was collected. That's in the process of being updated at the moment.

Q. So how would you know what the level of uptake was in that community?

A. We wouldn't have known nationally. It was the kind of thing that we asked local systems to report to us on, those that had local Gypsy, Roma and Traveller populations, we asked for sitrep information to say how that was working.

Q. And did you get it?

A. Yes, we would -- I would -- not at a level I'd want to report in national statistics, I don't think the national statistician would think it was robust, but it gave us an indication of the kind of thing that was happening, partly so we could share that with systems that were perhaps further behind. [9/191/4-25]

- 38. Dame Emily stated in her evidence that ethnicity data was in the process of being updated but the Chair will recall that Ms MacNamara also said that her organisation has been calling for the inclusion of GRT in the NHS Data Dictionary since 2012. [3/38/15]
- 39. It is submitted that it is unacceptable that this situation is permitted to continue. As stated on behalf of the Traveller Movement in oral closing submissions on 30 January 2025, if the Inquiry is to make any recommendation in relation to GRT it must emphatically recommend that that the NHS changes its data recording procedures to include the GRT communities.

- 40. The Traveller Movement maintains that it is self-evident data capture has a strong bearing on vaccine uptake. The Chair will recall that Ms McNamara told the Inquiry on 16<sup>th</sup> January 2025 that without proper data capture GRT community members would be effectively invisible. They would not have received NHS text messages that were sent out to vulnerable communities during the pandemic. [3/25/10].
- 41. Furthermore, Dr Kasstan-Dabush referred to GRT in his evidence on 28<sup>th</sup> January 2025 and said that you need an NHS number to be called up in the first place. [10/193/13-20]
- 42. The Traveller Movement's position (which ought to be uncontentious) is that without inclusion in NHS data, members of the Gypsy, Roma and Traveller communities will continue to be overlooked in local and national health strategies and delivery. That is what happened in the Covid pandemic and it will happen again, if not addressed.

#### Handheld records - GP registration

- 43. Ms MacNamara raised a further issue in her evidence, which is relevant to the question of low vaccine uptake in the GRT communities. She stated that GRT are no longer provided with handheld medical records. This had been a measure that addressed the longstanding problem of inclusion in healthcare that GRT face, where GRT community members relocate frequently between sites or houses. [3/27-28/18-2].
- 44. Accordingly, the Traveller Movement requests that the Inquiry recommends that the system of providing handheld records for members of the GRT communities is restored. These records would make it easier to register with a GP and might break the pattern of Travellers being turned away from surgeries. GP registration is important because (as Ms Stephenson put to Ms MacNamara on 16<sup>th</sup> January), the invitations to vaccinate were linked to GP registration; if you're excluded from that system you're just not getting the information [3/28/10-15]. It is noteworthy that many GRT did not have an NHS number during the pandemic, and that in itself amounted to an impediment to obtaining a vaccination.

## Conclusions – Three recommendations sought.

- 45. In conclusion, the Traveller Movement seeks three recommendations to improve immunisation uptake amongst the GRT communities. These are:
  - (i) That steps are taken to foster and maintain trust within Traveller groups locally. Such steps would include meaningful engagement by local authorities with GRT community leaders and provision of healthcare workers who understand the communities, and to whom GRT members can reach out for assurance around government programmes that affect them, such as vaccination programmes. Other initiatives would include GRT representation in government stakeholder and roundtable meetings.
  - (ii) Specialist health attendances on GRT. Yvonne MacNamara referred at the conclusion of her evidence to the need for a national framework for better development of mobile outreach services. It is clear that mobile vaccination clinics would facilitate vaccination uptake of GRT living on registered and unregistered sites. Furthermore, better engagement with medical authorities would enable GRT to retain handheld records, which would enable people to access vaccination through an easier GP registration process.
  - (iii) <u>High-quality data</u>. The NHS must capture GRT ethnicity in its records and data dictionary.
- 46. Ms MacNamara raised these three issues during her evidence on 16<sup>th</sup> January 2025 and made the point that vaccine uptake by the GRT communities would have been significantly better had those actions been implemented prior to Covid-19:

"Now, had they (GRT) been captured in local data, had there been a mobile service in place, had that trust been in place, we may not have had a lot of the issues that arose... right across the country for these communities. And I can absolutely guarantee you that uptake of the vaccine would have been much better." [3/32/15-21]

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47. Having heard the evidence and submissions from 14th to 31st January 2025, it should now be uncontentious that unless the authorities take the steps, which the Traveller

Movements asks the Inquiry to recommend - the mistakes that were made around

vaccination in the Covid-19 pandemic will be carried through into any future pandemic.

48. The Traveller Movement asks that the Chair recommends in her report that these

measures are implemented by policy makers now.

49. The evidence of the experts on vaccine delivery and disparities in coverage both

confirmed in their evidence that the problem of low vaccine uptake in minority

communities is a current problem and not a matter to be considered in a future

scenario. Dr Kasstan-Dabush told the Inquiry on 28th January 2025 that there is a

need to create an agenda for change:

" ....... think it's really crucial to ensure that changes happen when they're

needed, to learn from past limitations, shall we say, or failings, and create an

agenda for change in partnership with those underserved groups." [10/177/20-24]

50. Dr Chantler also took the view that problems relating to low vaccine uptake do not just

arise when there is a pandemic on the horizon. The Inquiry is referred to the following

exchange towards the conclusion of Dr Chantler's evidence on 28th January 2025

(emphasis added):

DR CHANTLER: Yes, yes. And we did reach higher levels in certain population

groups. I mean, the -- in white population groups we were up to 97%. I think what

is really important is that we did not reach that threshold level in all marginalised

communities. And also, yes, those are based on the two doses, but then, you

know, for all eligible vaccines the numbers drop over time. We cannot be

complacent. We have to be continuously promoting uptake of vaccinations.

Q. So that's very clear. It is possible to get to higher rates in certain communities,

and therefore it should be possible, and it needs to be made to be possible, in

relation to all other communities, so that they can get the public health benefit?

DR CHANTLER: Yes.

Q. That's the position. All right

DR CHANTLER: And it needs to be resourced, as well. [10/200/1-17]

51. Finally, the Traveller Movement submits that the Covid-19 Inquiry represents a once in a generation opportunity to address vaccine inequality within these three highly marginalised and vulnerable communities. It is respectfully submitted that the Inquiry must make robust recommendations to ensure GRT engagement and inclusion in the future. We repeat Ms MacNamara's statement: 'You can't build the Ark after the flood has happened'. That building process must start now.

CHRISTOPHER JACOBS

LANDMARK CHAMBERS

Howe + Co Solicitors

13th February 2025