

Approach and Recommendations for COVID-19 Vaccination Prioritisation & Roll Out for Travellers and Roma

"It's not just COVID-19 that is killing people, it's underprivilege, it's lack of access, it's years of living with health conditions that haven't been properly managed because of the colour of your skin, or your ethnicity, or your social group"- Dr. Mike Ryan, WHO¹, 2020

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Pavee Point Traveller and Roma Centre

Pavee Point Traveller and Roma Centre ('Pavee Point') have been working to challenge racism and promote Traveller and Roma inclusion in Ireland since 1985. The organisation works from a community development perspective and promotes the realisation of human rights and equality for Travellers and Roma in Ireland. The organisation is comprised of Travellers, Roma and members of the majority population, who work together in partnership to address the needs of Travellers and Roma as minority ethnic groups experiencing exclusion, marginalisation and racism. Working for social justice, solidarity and human rights, the central aim of Pavee Point is to contribute to improvement in the quality of life and living circumstances of Irish Travellers and Roma.

For further information contact:

Ronnie Fay, Co-Director ronnie.fay@pavee.ie
Tel: (086) 607 3197

¹ Interview with Dr. Mike Ryan

"Greater efforts must be put in place now to ensure that Traveller/Roma people are included in society and that they have equal access to the basic needs, thus ensuring their protection against infection. We need to stand united. The only way to overcome the crisis is by working together. If there can be anything more contagious than a virus, it is our solidarity. Europeans need to stand up for each other now."

Vice President of the European Commission Věra Jourová and Commissioner Helena Dalli, 2020²

Introduction

This briefing paper has been developed by Pavee Point to highlight the need for Travellers and Roma to be prioritised for access to COVID-19 vaccinations. We believe that there is a clear and urgent need for this prioritisation given the level of health inequalities, including higher rates of chronic health diseases, severely overcrowded and unsafe living conditions and the disproportionate impact COVID-19 has already had on both Travellers and Roma as acknowledged by the Government,³ Department of Health⁴, HSE⁵ and a range of international bodies.⁶

We welcome the Government's current vaccination programme targeting health care personnel and people in hospitals and long-term care facilities. We also welcome the *Ethical Framework for Decision Making in a Pandemic*⁷ and the supporting values underpinning the approach to vaccine prioritisation/rollout, in particular the commitment to fairness, equity and justice⁸ and the acknowledgement of the need to address structural inequalities, those at high risk of disease and those systematically marginalised. Clearly the application of this principle means that Travellers and Roma will be prioritised given the evidence we have on their situation in Ireland.

"While the principle of equity or fairness requires that like cases are treated alike in accordance with transparent criteria avoiding inequity requires ensuring that public health measures which are implemented during a pandemic focus on protecting the interests of populations who are considered vulnerable including those who typically encounter barriers to accessing care." **Department of Health, 2020**⁹

While the absence of official disaggregated ethnic data in Ireland makes it difficult to accurately capture the true impact of COVID-19 on the Traveller and Roma communities, the limited data we have, coupled with reports from Traveller organisations throughout the country, indicates that Traveller and Roma communities disproportionately higher positive rates of COVID-19 when compared to the national figures. We appreciate and are mindful of the challenges facing the Department of Health and Government in making decisions as to vaccine prioritisation, however, we believe there is a compelling case, and evidence, as to why Travellers and Roma need to be prioritised, both from a human rights perspective but, importantly, also to protect public health. Travellers and Roma comprise a relatively small population (approximately 36,000 Travellers and 5000 Roma in Ireland) and therefore it should not be a huge logistical exercise to organise.

² International Roma Day: Joint Statement by Vice-President Věra Jourová and Commissioner Helena Dalli

³ Department of An Taoiseach (2020), 'Report of the Social Implications of COVID-19 in Ireland.'

Preliminary Assessment,' available at: https://assets.gov.ie/74373/5cc1bbfe59b447d3b841fa43cecfc79d.pdf

⁴ Department of Health (2020), 'Statement from the National Public Health Emergency Team – Tuesday 24 March,' available at: https://www.gov.ie/en/press-release/e378fd-statement-from-the-national-public-health-emergency-team-on-tuesday-/

⁵ See <u>here</u> and <u>here</u>

⁶ See statements from the <u>Council of Europe</u>; <u>OSCE</u>; and <u>FRA</u>

⁷ Ethical framework for decision-making in a pandemic

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⁹ Ethical framework for decision-making in a pandemic

"The existing vulnerabilities of members of the Traveller and Roma communities in health and accommodation put them at particular risk of contracting the virus. Maintaining social distancing and self-isolation is challenging in some living environments, as is access to appropriate community health services and resources that can meet their needs. Members of the Roma community also have difficulty in accessing social supports to meet basic needs." **Department of An Taoiseach, 2020**

In this paper we firstly highlight the reasons why Travellers and Roma need to be prioritised in the vaccination programme. Secondly, we highlight issues that we have identified, thus far, that need to be addressed to ensure the effective roll-out of the vaccination programme among Travellers and Roma communities.

1. Ensuring a nationally consistent approach to the rollout of COVID-19 vaccination to Traveller and Roma communities

Critical to mitigating COVID-19 within the Traveller and Roma communities during this pandemic has been the partnership approach adopted by the HSE, government departments and Traveller organisations. The level of interdepartmental work has enabled some timely and effective COVID-19 responses to date. It is essential that this consistent national approach is also applied to the rollout of the COVID-19 vaccination to Traveller and Roma communities.

The National COVID 19 Strategy aims to ensure that the most vulnerable people in our society and those at highest risk¹⁰ of contracting COVID-19 are prioritised for vaccination. It is evident that Travellers and Roma are one of these key priority groups, as the COVID-19 pandemic has had a disproportionate impact on both communities, with the rates of testing positive for COVID-19 significantly higher than the national figure.

2. Contextual Reasons for Traveller and Roma Prioritisation

Before the pandemic, Travellers and Roma were experiencing poorer health outcomes; extreme poverty; poor and overcrowded accommodation; high levels of unemployment; significant levels of discrimination and racism; and a lack of access to mainstream services. These issues have been further exacerbated during this crisis and have increased their vulnerability to contracting and becoming ill with the COVID-19 virus.

 Health Inequalities: Research shows the stark inequalities for Travellers and Roma in relation to access, participation and outcomes in health. The All Ireland Traveller Health Study (AITHS) highlights that the community is particularly at risk of dying from respiratory illnesses, cardiovascular diseases, and suicide.¹²

Access to adequate healthcare has been highlighted as a particular challenge for Roma in Ireland. The *National Roma Needs Assessment* found more than 1 in 3 Roma do not have a GP and 50% do not have a medical card¹³.

• Living Conditions: Travellers and Roma are more likely to live in over-crowded and substandard accommodation. The European FRA survey¹⁴ found 24% of Travellers face severe housing deprivation, which is 30 times more than people generally in Ireland (0.8%). 56% of Travellers live in overcrowded conditions compared to just 8% of non-

¹⁰ In this instance, due to poor or non-existent sanitation, severely overcrowded living conditions and low levels of basic health – especially respiratory conditions such as asthma or COPD.

¹¹ FRA (2019) Travellers in Ireland Study

¹² National Traveller and Roma Inclusion Strategy (2017 - 2021), p. 11

¹³ National Roma Needs Assessment 2018

¹⁴ FRA (2019) Travellers in Ireland Study

Travellers.¹⁵ Additionally, many Travellers live in 'unauthorised sites' where they are not provided with basic facilities such as electricity and water. Similarly, housing and homelessness are also significant issues for Roma. Data from the *National Roma Needs Assessment* in Ireland found that 6.6% of Roma reported they were currently homeless and 45.7% had been homeless at some stage. In addition, 24% were living in overcrowded households of eight or more people, and 44.8% did not have enough beds in their accommodation¹⁶.

These living conditions not only make social distancing extremely difficult for Travellers and Roma, if not impossible in many cases, but a lack of sanitation facilities also impacts on people being able to adhere to the COVID-19 handwashing advice.

• Family Sizes: It is very common for Travellers and Roma to live in large and extended family units, ¹⁷ often living in multiple, inter-generational units, where up to three or even four generations of an extended family could live alongside each other. Large family units, coupled with crowded living conditions, makes it nigh on nearly impossible for those testing positive with COVID-19 or those identified as a close contact, to follow the HSE's self-isolation guidelines.

3. Prioritisation of Traveller Primary Health Care Workers as Frontline Health Care Workers

Pavee Point established its Traveller Primary Health Care Project (PHCPs) more than 25 years ago and today there are approximately 27 such projects operating throughout the country. Traveller Primary Health Care Workers (PHCWs) who are employed in these projects have delivered peer-led health education, promoting positive health outcomes for the Traveller community as a whole. The employment of PHCWs to provide primary health care to the Traveller Community has been demonstrated to be an effective approach in bridging the gap between a community experiencing high health inequalities and a health service unable to reach and engage that community effectively in health service provision. This approach has also been proven internationally as an effective method of engaging and including minority ethnic groups in health service provision.

These PHCWs have continued to play an integral role in improving Traveller health outcomes during the COVID-19 pandemic¹⁸. They have worked tirelessly in their communities to disseminate public health guidance, create a wealth of Traveller-specific resources and provide Personal Protection Equipment (PPE). The Traveller PHCWs have also utilised their local knowledge and their positions of trust in the community to support the HSE on the ground, through Safety Net, National Ambulance Service and Swift Queue, with targeted and masstesting.

Traveller PHCWs are working on the frontlines during this pandemic and as such, must be included in the prioritisation of vaccines alongside other frontline health care workers in current priority 2¹⁹. This will support the continuation of the important public health work provided by the Traveller Primary Health Care Projects. Additionally, the early vaccination of Traveller PHCWs will also assist in convincing other members of the community of the vaccine's safety and efficacy.

¹⁵ ESRI Report: A Social Portrait of Travellers in Ireland (2017), p. 45

¹⁶ National Roma Needs Assessment 2018

^{17 2016} Census

¹⁸ https://www.hse.ie/eng/about/who/primarycare/socialinclusion/travellers-and-roma/

¹⁹ https://www.gov.ie/en/publication/39038-provisional-vaccine-allocation-groups/

4. Absence of Ethnic Data

The European Commission, the European Union (EU) Agency for Fundamental Rights, the Organization for Security and Co-operation in Europe Office for Democratic Institutions and Human Rights, and the Council of Europe issued statements²⁰ drawing attention to the disproportionate impact of COVID-19 on Travellers and Roma throughout Europe and the lack of real-time ethnic data to properly monitor the crisis. In Ireland, the impact of COVID-19 on Traveller and Roma communities continues to be underreported in the absence of ethnic equality monitoring, inclusive of disaggregated ethnic data.

"Collection, disaggregation and analysis of data by ethnicity or race, as well as gender, are essential to identify and address inequalities and structural discrimination that contributes to poor health outcomes, including for COVID 19."

UN High Commissioner for Human Rights Michelle Bachelet, 2020²¹

There is an urgent need to ensure that our data collection systems related to COVID-19 includes and implements an ethnic identifier using a human rights framework²². This is vital in order to evaluate and document the impact of the virus on both Traveller and Roma communities as otherwise the actual severity of the impact on these communities will continue to remain unknown.

5. Ensuring the Prioritisation of 'Older 'Travellers and Roma

The HSE's prioritisation strategy seeks to initially target the over 65's living in long-term care facilities due to their vulnerability to the virus and the risks associated with living in congregated settings. This is followed by frontline health care workers and those aged 70 and older. Pavee Point is concerned that the majority of Travellers and Roma will be excluded from these priority groups (by proxy)due to the following:

- Lower Life Expectancies: Only 3% of Travellers live to 65 years of age²³ (compared to 11% of the general population), and European Studies estimate that Roma life expectancy is between 5 and 20 years less than the majority population²⁴
- Very few older Travellers or Roma live in long-term care facilities as they are usually cared for by extended family, and
- Challenges in identifying Travellers and Roma within the community in absence of ethnic data being recorded and/or implemented on GP and other health data administrative systems

We would further argue that many Travellers and Roma will meet the threshold for vulnerability to COVID-19 due to their poorer health outcomes and overcrowded and sub-standard living conditions. Also, in recognition of Travellers' lower life expectancy, which the Department of Health acknowledged in setting out its indicators for positive ageing of Travellers²⁵ redefines "Traveller 'ageing' as 40+,"²⁶ we recommend that this cohort of Travellers and Roma (40+) should be identified as a priority group for the vaccine.

6. 'Prioritisation within Priority Groups'

Ensuring the prioritisation of Travellers and Roma within the Categories/Sequencing for rollout of the vaccines. Given their multiple vulnerabilities, including existing pre COVID-19 health inequalities; poor

²⁴ 2018 European Public Health Alliance

²⁰ See statements from the Council of Europe; OSCE; and FRA

 $^{^{21}\} https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25916$

²² Policy and Practice in Ethnic Data Collection and Monitoring

²³ 2016 Census

²⁵ Healthy and Positive Ageing Initiative of Travellers. Developing Indicators of Positive Ageing for Irish Travellers

²⁶ Healthy and Positive Ageing Initiative of Travellers. Developing Indicators of Positive Ageing for Irish Travellers

living conditions and associated challenges to self-isolate; as well as being highly mobile populations, it is in the interest of public health protection measures that Travellers and Roma are prioritised within the priority groups for rollout of vaccinations.

7. User Friendly Vaccine Registration Processes

Depending on what the plans are for registering for vaccinations there are likely to be specific challenges within Traveller and Roma communities. These might relate to literacy levels if forms need to be completed; technology challenges if the portal is to be used given the lack of computers, access to WIFI on sites and digital skills deficit among these communities; specific language challenges for Roma; trust in giving PPSNs to strangers, and for Roma even having a PPSN; rollout through GPs and pharmacies may not be the most effective mechanism for many Travellers and Roma. We have received many reports of Travellers unsuccessfully trying to contact GPs directly to be referred for testing throughout COVID-19.

Further, the *National Roma Needs Assessment* found more than 1 in 3 Roma do not have a GP and 50% do not have a medical card²⁷. It is clear that a mainstreaming approach only is not sufficient to ensure equity and therefore targeted measures may need to be developed to identify the most efficient mechanism for Travellers and Roma to be vaccinated. Consideration could be given to including outreach vaccination clinics in local community settings or on sites if possible. Once we are clearer on the proposed rollout plans, Pavee Point would be willing to 'Traveller/Roma-proof' them in consultation with other Traveller organisations, Traveller Primary Health Care Projects and groups working with Roma. It is imperative that a user friendly and streamlined pathway for registration is used in vaccination rollout plans. Equally, it will be important that data on ethnicity is collected in these processes.

8. Challenges to Vaccination Rollout among Traveller and Roma Communities

Pavee Point is working with Traveller and Roma communities to promote the uptake of the approved COVID-19 vaccinations and to build confidence in these processes. This requires a targeted and collaborative approach, with state agencies, health professionals, and Traveller organisations and groups working with Roma.

Vaccination hesitancy is a significant issue for the national COVID-19 vaccine rollout, and recent international evidence suggests this is much more prevalent amongst minority ethnic groups²⁸, including Travellers and Roma. Many Travellers and Roma do not access mainstream news media outlets and often use social media for access to information. We are already receiving reports of fears and concerns about the COVID-19 vaccination. Some contributing factors are:

- Travellers and Roma are particularly fearful of vaccination because of how quickly it was developed, manufactured and approved
- Myth that you don't need the vaccine if you have tested positive for COVID-19 as you can't get COVID-19 twice
- Vaccine misinformation on social media
- Lack of culturally appropriate and accessible information
- Lack of trust in health services: this is particularly true for the Roma community who have recent lived experience in their countries of origin of medical testing/experimentation, and forced sterilisation²⁹

²⁷ National Roma Needs Assessment 2018

²⁸ See for example, in the U.S <u>here</u> and <u>here</u>; and the <u>UK</u>

²⁹ Forced sterilisation policies for Roma in Europe have been documented in Hungary, Romania, Bulgaria, Czech Republic and Slovakia. See here and

- Misleading messages from religious sites that may be used by Travellers and Roma (e.g. "Be careful of campaigns of mass vaccinations" from Our Lady of Medjugorje³⁰). In addition, there can also be misleading advice from some perceived and trusted religious individuals. Traveller organisations shared information on the Pope receiving the vaccination to debunk vaccine myths and, however the positive response we anticipated from this was not forthcoming
- Travellers want to know more about the vaccine what's in it?

To counteract the circulating myths and misconceptions, it is important that the Government works closely with Traveller organisations and groups working with Roma to build confidence in vaccinations and to develop culturally appropriate vaccination education materials. It is also vital that frontline Traveller Primary Health Care Workers, and other Traveller and Roma community workers and leaders, can play a role in informing the community of the safety and efficacy of the vaccines. It was clearly illustrated in the recent 'HSE National COVID-19 Traveller Service User Experience Survey' conducted by the National Social Inclusion office, that 'the vast majority' of Travellers obtained information about COVID-19 through their local Traveller project (73%).³¹

Travellers and Roma should also be visible in mainstream public health education campaigns. We are working hard to share public health information on the vaccines and to build confidence in Traveller and Roma communities to get vaccinated. Consideration should be given to the establishment of a dedicated COVID-19 vaccination support contact centre, which functions to inform and reassure vulnerable populations, including Travellers and Roma.

9. Perception of quality/efficacy of vaccines

As noted above, given the well-documented lower levels of trust in mainstream health services for both Travellers and Roma, we have been receiving reports of concerns in relation to trust in vaccinations. Therefore, it will be important to ensure that for those Travellers and Roma who choose to be vaccinated, there is no perception that they are being given vaccines that are less efficacious and effective than others. This fear is already being articulated, that Travellers and Roma will be given 'faulty' vaccines and/or used as 'guinea pigs'.

Conclusion

We appreciate and are mindful of the challenges facing the Department of Health and Government in making decisions as to vaccine prioritisation, however we believe there is a clear and compelling case, and evidence, as to why Travellers and Roma must be prioritised, both from a human rights perspective but, importantly, also to protect public health. Travellers and Roma are a relatively small population (approximately 36,000 Travellers and 5,000 Roma in Ireland) and therefore it would not be a huge logistical exercise to organise. Throughout the pandemic Pavee Point and other Traveller organisations and Primary Health Care Projects, as well as groups working with Roma, have worked tirelessly with the HSE and a range of stakeholders to mitigate the worst of the impact of COVID-19 on the Traveller and Roma communities. We are committed to continue to do so in the roll out of vaccinations and make recommendations below:

³⁰ See http://www.jesusmariasite.org/be-careful-about-campaigns-of-mass-vaccination/

³¹ National COVID-19 Traveller Service User Experience Survey

Recommendations

- Adopt a consistent national approach, including special measures, across all CHOs to vaccinating vulnerable Traveller and Roma communities
- Prioritise the vaccination of Traveller and Roma populations, considering the population's life expectancy, poor health outcomes, and overcrowded/sub-standard, congregated living conditions
- Prioritisation of Traveller Primary Health Care Workers as frontline workers in need of early vaccination
- Positive action measures, including the application of Department of Health Positive Ageing Indicators, whereby older Travellers and Roma can access the vaccine at a lower age bracket (40+) given only 3% of Travellers live over 65 years
- Include **and implement** an ethnic identifier for Travellers and Roma on the healthlink system, CIDR/CRM and in vaccination data surveillance and IT systems³²
- Travellers and Roma are recognised, prioritised and named within the priority groups listed for rollout of vaccinations
- Work in partnership with Traveller organisations and groups working with Roma in the development and dissemination of culturally appropriate health education information and building confidence with respect to COVID-19 vaccinations
- Ensure visibility of Travellers and Roma in mainstream vaccination education campaigns
- Consideration could be given to including the organisation of outreach vaccination clinics in local community settings or on sites
- Establish a dedicated COVID-19 vaccination support contact centre, which functions to inform and reassure vulnerable populations, including Travellers and Roma

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³² As per the National COVID-19 Vaccination Programme: Strategy