

**April 2025** 

Methodology report of vaccination films for Gypsy, Roma and Traveller communities



This report was developed through funding by UKHSA Health Equity and Inclusion Health Division. This report does not necessarily reflect the views of UKHSA. Report compiled by Michelle Gavin and Lilia Bernard from Friends, Families and Travellers.

# **Executive Summary**

As part of UK Health Security Agency's (UKHSA) mission to protect all members of the population from infectious diseases and reduce health inequalities, UKHSA commissioned Friends, Families and Travellers (FFT) to engage in a co-production project to develop vaccination resources by and for Gypsy, Roma and Traveller communities, recognising that vaccination coverage can be low. This report describes the co-production process and seeks to draw key lessons that can inform future co-production activities.

The co-production process of creating vaccination films for Gypsy, Roma and Traveller audiences included a lived experience panel and community input to codesign the content and creation of the films. Barriers to vaccination highlighted by people with lived experience was important to address when developing these films, including system barriers such as registering with and accessing primary care; cultural perceptions of not routinely needing to access ante-natal care / interventions (i.e. vaccinations) due to pregnancy being a normal and healthy condition; compounding challenges facing migrant groups (i.e. high proportion of the Roma community).

In communicating about vaccination, findings were that the films needed to represent the language and diversity of Gypsy, Roma and Traveller communities as much as possible. This included terminology and language, visual imagery, and narration. Recruitment of community members as narrators and translators was limited by literacy barriers, confidentiality concerns, and hesitance about promoting vaccination.



The process of co-production built trust with participants, leading to positive feedback about the project, as well as delivering accessible and community-grounded resources. Agreeing scripts and films that met the needs of all parties was a complex process and placed significant pressure on delivering the project within a short timeframe.

Recommendations for strengthening co-development or co-production of communication materials include building in more flexibility around scripts, strong co-ordination between partners, and including buffer zones during timeframe building.

## **Background**

Friends, Families and Travellers, a national charity supporting Gypsy, Roma and Traveller people, was commissioned by UKHSA to co-develop culturally relevant vaccine resources. Previous investigations highlighted the need for communication resources tailored for and co-produced by Gypsy, Roma and Traveller communities.

Research has shown that vaccination uptake, and other preventative measures, is lower in Gypsy, Roma and Traveller communities. Previous engagement with Gypsy, Roma and Traveller communities helped inform the best formats and content for communication materials aimed at promoting maternal and childhood vaccination.

This project builds on those insights to co-create evergreen (materials that remain relevant for an extended period of time) video and audio resources specifically for Gypsy, Roma and Traveller communities. By making the resources evergreen, it ensures that thoughtful material can be rolled out in a proactive manner rather than a reactive one.



#### **Methods**

#### Lived experience panel and community input

Community members were recruited to lead a steering panel to ensure ownership and authenticity in the development of resources. FFT partnered with the Roma Support Group to recruit participants from the Roma community, drawing on their expertise and established reach within that community. The panel comprised of seven women from different community backgrounds, including Irish Travellers, Roma, a Romany Gypsy, and a New Traveller, aged between 30 and 67. Members of the steering panel lived across various housing situations, including bricks-and-mortar housing and local authority sites. The aim of the panel was to guide the stages of the project, ensuring that the resources were shaped by lived experience.

Two focus groups were conducted in January 2025, with a total of 15 participants from diverse community backgrounds, including Irish Travellers, Romany Gypsy, Roma, New Travellers and a Liveaboard Boater. Participants came from a range of living situations, including bricks-and-mortar housing, local authority sites, and a private boat yard. Participants shared their personal experiences with vaccinations, their understanding of immunisation and the barriers they face in accessing vaccine programmes. The focus groups provided valuable insights into terminology, preferred formats, and visual representations.

To refine the resources, three co-production workshops were hosted by FFT with community members and the project illustrator, also a community member. The first workshop concentrated on the development of scripts, focusing on culturally appropriate language and the framing of health advice. We presented previous immunisation campaigns and resources to learn more about their views on the messaging used. The following workshops helped establish the visual elements of the resources, ensuring the illustrations were representative, warm, and culturally resonant. These sessions also included discussions around branding and logos, with participants expressing a stronger preference and trust for the NHS logo over the UKHSA logo. The concerns about the UKHSA branding centred on the word



'security', which evoked associations with authority and control. The concern was that this could reinforce existing mistrust, rooted in historical experiences.

Once the illustrations were drafted, we reconvened the steering panel for them to review the illustrations and provide further feedback. A suggestion, put forward by the steering panel and presented to the focus group, was the inclusion of a testimonial film featuring elders. Within Gypsy, Roma and Traveller communities, elders are considered respected and trusted figures, and they felt that hearing stories from older generations who witnessed the impacts of illness before vaccines were common, would build trust within the communities.

## **Quotes from focus groups**

- "My mum and dad have never had any, no one in my family had any. So, I
  didn't get any for my kids at all. We just don't vaccinate in our family."
- "They travelled so much, it just wasn't easy to keep track of our vaccines."
- "The trouble is many people don't have a record of vaccines, and they really worry about if children are vaccinated again, if they could sort of pose some sort of safety risk."
- "My mother was really angry with me because she said, being older, you know, you don't know what it was like to when my friends had polio. You know, then, she was talking the truth."
- "But I think, you know, everyone has the right to obviously say no. But I think that these sorts of vaccines are pretty safe."

#### **Ethics and Data Protection**

All participants involved in the focus groups, workshops, and filming were provided with participant information sheets which outlined the purpose of the project, the nature of their involvement, data handling practices, and their right to withdraw from the project. These documents were also read aloud to ensure comprehension, as some participants had low literacy levels. Each participant gave informed consent using detailed consent forms that addressed data collection, audio recording and the anonymised use of quotes in final resources.



Personal information was collected through a demographic and consent form, completed voluntarily. This included age, gender, location, housing type, and community affiliation, as well as optional date on ethnicity, religion, health conditions, and sexual orientation. All information is stored securely on FFT's internal systems in line with UK GDPR regulations.

#### Translations and Voiceover Work

Translators and community members were recruited to deliver authentic, community-rooted audio content. The English voiceovers were recorded by a New Traveller, a Romany Gypsy and an Irish Traveller.

The diversity within the different communities means that the scripts had to be tailored to meet the specific needs of Gypsy, Roma and Traveller groups. Our collaboration with Roma Support Group (RSG) was essential for the content to be accurate and culturally relevant for Roma communities. RSG ensured that the resources were translated into three Roma dialects:

- Slovak Romanes
- o Polish Romanes
- Romanian Romanes

The translated films will ensure that the information is accessible to a broader section of the Roma community and will support vaccine uptake across diverse linguistic groups.

# **Findings**

## Findings from the community engagement process

Community members responded positively to the opportunity to co-develop resources. Participants appreciated the importance of developing resources to ensure that accurate information was accessible. They emphasised the importance of using community-specific language to ensure understanding and cultural



relevance. However, as the Gypsy, Roma and Traveller communities are diverse, community-preferred terminology does vary. For example, Irish Travellers used the term "needle", Romany Gypsies used "jab", and Roma communities used "vaccine".

Due to the low literacy rates, communications about vaccinations have often previously been inaccessible. Individuals, therefore, lack access to accurate information, leaving them with unanswered questions about vaccines. In the absence of information from trusted sources, people seek answers from elsewhere, exposing themselves to misinformation. The need for clear and accessible explanations was emphasised by participants. One participant, noted about vaccines:

• "When they [health visitors] explained to all the parents how dangerous it was [measles], the nurse was brought to site and they [the children] all had them".

Co-producing tailored communications for Gypsy, Roma and Traveller communities helps build trust among the communities, which is essential for supporting vaccination uptake.

For the visual material, participants encouraged the inclusion of culturally representative characters and scenes that mirrored their ways of living, such as caravans, large multi-generational families, and gatherings. They expressed a preference for vibrant, warm imagery and visual metaphors like protective halos around the mother and children. The choice of illustrated films made it possible for information to be presented in a light and welcoming way, ensuring that the resources did not come across as patronising or coercive. Participants argued that the scripts should emphasise that vaccines are a choice and are free and accessible.

It was important to ensure that the films were non-judgemental, creating a positive and reassuring experience for the audience.



#### Vaccine uptake barriers

Several barriers to vaccine uptake emerged, many tied to systemic issues and cultural understandings. Vaccination programmes are often delivered through GPs. Yet, many people from Gypsy, Roma and Traveller communities are not registered with a GP¹ and so are not invited for vaccinations when they are due. Many participants also lacked vaccination records due to their nomadic way of life. This is particularly the case within Roma communities with overseas medical records.

The Roma community faced specific barriers and concerns due to the common status as migrants. Participants described frequent difficulties accessing healthcare services because of a lack of documentation, language barriers and uncertainties around entitlements within the NHS. In some cases, families were unaware of the right to register with a GP without needing proof of address, identification or proof of immigration status. Additionally, in the case of pregnancy vaccines, within Roma communities, a pregnancy is perceived as a natural and positive condition that does not require medical attention. As such, engagement with antenatal care services where vaccination information would otherwise be provided is low.

## Findings from the filming process

Amending and editing scripts within tight deadlines while ensuring the accuracy of the content has been a significant challenge. Since the videos were intended to be short and engaging, this limited the amount of information that could be realistically included. This required thoughtful decisions about what to prioritise, while ensuring that the scripts remained clear, accurate and culturally sensitive without overwhelming the viewer and losing engagement.

As a complex project with many subject matter experts, it was important to ensure that scripts were in line with public health guidance. However, this was challenging in the context of short timelines, lengthy sign-off processes and a large oversight group

<sup>&</sup>lt;sup>1</sup> Either due to a lack if fixed address and/or stigma and discrimination.



with various levels of involvement. This highlighted the importance of having a key point of contact within the agency to help to coordinate inputs.

Filming and recording presented practical challenges. Literacy barriers made script reading difficult, despite the efforts to simplify the language. One narrator still found the scripts formal and unnatural to read aloud, which impacted their capacity to maintain a natural tone. Furthermore, community members were hesitant to be recorded as they were concerned about being recognised and associated with vaccine messaging in their communities. This was also a challenge in recruiting Roma translators. In turn, this limited the pool of volunteers for the recordings of the voiceovers. During the scheduled recording period, both community narrators became ill. This setback required a deadline extension to ensure that the films were representative of the communities. UKHSA was very helpful and understanding throughout these challenges and made the necessary adjustments to ensure the project's success.

However, developing animated videos allowed for more flexibility for the same scripts to be narrated in different languages and dialects. Each translation differed in length from the English scripts. Using animation meant we could easily adjust the timing and length of the films to accommodate each language.

### **Communication Plan**

To maximise reach, the resources will be promoted through a multi-channel dissemination strategy:

- The films will be hosted on FFT's YouTube channel.
- The films will be promoted across FFT's social media platforms, including X
  (formerly Twitter), Instagram, TikTok and LinkedIn (via FFT's page and key
  staff accounts).
- The films will be shared on FFT's national Facebook page and circulated in closed community Facebook groups for Gypsy, Roma and Traveller community members.



- FFT's newsletter will announce the launch of the resources to reach our broad network of subscribers.
- A press release will be published on FFT's website and circulated to partner organisations within Gypsy, Roma and Traveller civil society.
- The films will be featured in newsletters and platforms of partner groups, such as Irish in Britain.
- The resources will be shared through FFT's race quality networks, including the Equally Ours network
- The films will be distributed through the Health Wellbeing Alliance portal and cascaded through their networks.
- We will send the films to maternity service groups and ensure that they are cascaded to local maternity representatives
- The resources will also be shared with the Friendly Churches network for further reach within the communities.
- Roma Support Group will host the translated films on their platforms as they
  have a better reach of Roma communities.
- UKHSA communications team will work with NHSE comms team to further disseminate resources.
- The UKHSA Health Equity and Inclusion Health Team will work with the Health Equity Leads network, immunisation team, and comms team to shared resources internally.
- UKHSA will support FFT with a webinar to launch resources to external stakeholders
- UKHSA will feed findings from this project into insights for further comms work, incidents, or outbreaks.

# **Conclusion and Key Learnings**

The aim of the project was to co-produce targeted vaccine resources for Gypsy, Roma and Traveller communities. A co-development approach recognises the importance of designing public health messaging that is not only informative but culturally appropriate and shaped by lived experience. Incorporating community



insights to the design process helps build trust and ensures that resources effectively resonate with the communities.

The co-production process enables the creation of resources that are accessible and grounded in real concerns and preferences of the communities. The collaboration between UKHSA and FFT highlights the importance of inclusive public health approaches that actively involve those most affected by health inequalities. Tailored vaccination resources, by embedding the voices of inclusion health groups, not only foster trust but enhances the impact of public health guidance.

As we adopt more collaborative approaches, it is important to reflect on some of the challenges encountered. The following recommendations seek to improve future coproduction efforts:

- Build in flexibility around scripts future initiatives should consider the challenges that even simplified scripts can pose for communities with literacy barriers, as they may impact the flow of the message.
- Coordination with partners co-production approaches involve various stakeholders and thus require regular communication. To ensure efficient coordination and decision-making, stakeholders should all be well-briefed.
- Allow sufficient time to undertake co-production process recognising that feedback and sign off processes can affect timelines for finalisation of resources.
- FFT is used to working with government and NHS advisory committees, giving us confidence to push back. However, multiple departments and strong public health advisors can be intimidating, especially for organisations or VCSEs less familiar with these processes. Future collaboration could emphasise that it is a space to confidently justify decisions through lived experience. Protection is important, as critique heavy environments can feel demeaning and pressure participants to simply fall in line.

Developing and investing in more collaborative approaches is essential for engaging with people with lived experience and promoting trust within communities. UKHSA's



commitment to fostering collaboration is crucial to develop more culturally sensitive and impactful public health strategies.

## **About us**

Friends, Families and Travellers (FFT) is a leading national charity that seeks to end racism and discrimination against Gypsies, Travellers and Roma communities and to protect the right to pursue a nomadic way of life. <a href="www.gypsy-traveller.org">www.gypsy-traveller.org</a>
Tel +44 (0)1273 234 777 | Email <a href="mailto:fft@gypsy-traveller.org">fft@gypsy-traveller.org</a> | X <a href="@GypsyTravellers">@GypsyTravellers</a>
FB <a href="@FriendsFamiliesandTravellers">@FriendsFamiliesandTravellers</a> | BSKY <a href="@gft.bsky.social">@fft.bsky.social</a> | LinkedIn <a href="FFT">FFT</a>