UK Health Security Agency

# Pilot for improving uptake of PCR testing, lateral flow testing and support to self-isolate in Gypsy, Traveller and nomadic communities

## Evaluation for friends, families and Travellers

# Contents

# Introduction

As a result of pre-existing health inequalities, combined with high levels of poverty, overcrowding and historic issues related to accommodation, Gypsy and Traveller communities are at higher risk of being infected by COVID-19. At the same time, Gypsy and Traveller communities are known to face some of the most severe health inequalities and poor life outcomes amongst the UK population, which means there is a disproportionately high representation of people at increased risk of severe illness from COVID-19.

As a result of these disparities ensuring that members of Gypsy, Traveller and Boater communities were able to fully participate in the Government's testing scheme and self-isolation procedures is critical. However, throughout the COVID-19 crisis there have been considerable barriers observed by organisations working with members of these communities. Significant barriers noted by friends, families and Travellers (FFT) noted before the pilot included:

People living on roadside camps and boats being unable to access polymerase chain reaction (PCR) testing (both home testing and drive-in test centres) throughout the pandemic. For home kits this was largely attributed to having no fixed address. For drive-in test centres this was attributed to 4 main reasons: the continued use of eviction powers by authorities meaning people are less willing to leave a piece of land, rurality, lack of appropriate vehicles and limited vehicle height restrictions.

Difficulty accessing relevant information and messaging around self-isolation and testing as a result of barriers to accessible information for those with low or no literacy (members of Gypsy and Traveller communities have notably low levels of literacy), low levels of health literacy as a result of severe educational inequalities and continuing digital exclusion.

Concerns around loss of income as a result of self-isolation for those who are self-employed, engaged in seasonal work typical within Gypsy and Traveller communities and/or have low income.

Difficulty accessing water, sanitation and fuel when self-isolating for people living on roadside camps and boats.

Difficulty maintaining distance when self-isolating within confined living spaces, example a caravan, a van or a narrowboat

## About this evaluation

In 2021 the UK Health Security Agency (UKHSA) provided funding to FFT to establish a pilot assertive outreach service to link members of Gypsy and Traveller communities with support in order to help access testing processes and engage in self-isolation procedures.

The goal of the pilot was to directly improve access to testing for COVID-19 and enable self-isolation via outreach interventions. This included the promotion of rapid lateral flow testing, distribution of rapid lateral flow testing packs, support to access self-isolation payment, delivery of PCR tests, improving ability to self-isolate and improving knowledge on self-isolation requirements. In addition, the pilot aimed to gather relevant data and intelligence to address gaps in existing data on key barriers and solutions to testing and self-isolation for Gypsy and Traveller communities.

There were a number of outcomes which were anticipated from this pilot as follows:

- improved uptake of rapid lateral flow tests in target audience
- improved uptake of self-isolation payment in target audience
- improved uptake of PCR tests in target audience
- improved knowledge on self-isolation requirements within target audience
- improved adherence to self-isolation guidance within target audience
- improved knowledge amongst statutory and voluntary sector on barriers to testing and self-isolation for Gypsy and Traveller people and ways in which these can be overcome

As part of this pilot resource was provided to undertake an external evaluation of the process and outcomes.

# Evaluation questions

There were several questions posed at the outset of the evaluation to explore, these are as follows:

- did resource provided to established, assertive and trusted outreach services with existing links with Gypsy and Traveller communities support result in an improved access to and uptake of testing and self-isolation within Gypsy, Traveller and nomadic communities?
- to what extent can any outcomes or changes in uptake of testing or self-isolation be attributed to the pilot project?
- what specific barriers to testing and self-isolation for Gypsy, Traveller and nomadic communities exist, and did the pilot help to overcome these?
- what were the particular aspects of the pilot that made a difference to uptake or access to testing and self-isolation?
- what additional or unintended outcomes (positive or negative) did the pilot produce?

The outreach work as part of the pilot ran from October 2021 until the end of December 2021.

# Evaluation methodology

The evaluation presented in this report was based on the following data sources:

- secondary analysis of available data recorded in outreach logs by FFT workers
- interviews with project staff from FFT

## Secondary analysis of data supplied by FFT from outreach logs

The main body of the evaluation draws on the secondary data collected by FFT staff which reported their engagement with Gypsy and Traveller community members. This information recorded a number of pieces of information including:

- demographics
- household size
- accommodation status
- location
- self-reports on their experience of COVID-19
- their engagement with testing
- their vaccination and booster status
- their engagement with self-isolation
- knowledge about the testing process
- the outcome of the outreach visit
- their broader experience of the pandemic

## Interviews with project staff

Members of the project team were consulted to discuss their experiences of undertaking the outreach work. These discussions were held over the phone or online after their work had concluded in early 2022.

# Findings

The outreach team logged 121 contacts with Gypsy and Travellers during the pilot. From speaking to project workers, it is likely that the reach of the project was much wider than this due to the responsive nature of the service and the reach of FFTs social media platforms. However, these more dispersed engagements have not been recorded. The data below relates to recorded outreach engagements. These were recorded as individuals not households and so data will relate to a fewer number of separate households. However, it is not possible to identify the number of individual households from this data.

Furthermore, it was clear from speaking to project team members that data recording was inconsistent across the team.

# Demographic profile and background of the participants

There was a total of 32 women, 85 men and missing gender information for 4 participants. All participants who provided their gender, identified with that gender at birth although there were 11 participants where there is no information about their gender assignment.

Those contacted represented a diverse sample with the largest group identifying as Gypsy (41: 34%) followed by New Traveller (26: 21%) and Irish Traveller (24: 20%) with smaller number of participants from other groups. It should be noted that a total of 5 participants (4%) identified as non-Travellers (see Table 1).

**Table 1. Ethnic group of the participants**

| Ethnicity | Number | % |
|---|---|---|
| Gypsy | 41 | 34% |
| Traveller | 3 | 2% |
| Non-Traveller | 5 | 4% |
| New Traveller | 26 | 21% |
| Scottish Traveller | 1 | 1% |
| Welsh Traveller | 2 | 2% |
| English Traveller | 2 | 2% |
| Irish Traveller | 24 | 20% |
| Romany Gypsy | 6 | 5% |
| Missing information | 11 | 9% |
| Total | 121 | 100% |

The age range of participants was spread across the life course with the majority of participants in their 20s (32: 26%) followed by the 50s (31: 26%) and then 30s (25: 21%) with smaller numbers in other age categories. No participants took part in their 70s or who were older than 89 years of age (see Table 2).

**Table 2. Age range of the participants**

| Age range | Number | % |
|---|---|---|
| 20s | 32 | 26% |
| 30s | 25 | 21% |
| 40s | 19 | 16% |

| Age range | Number | % |
|---|---|---|
| 50s | 31 | 26% |
| 60s | 9 | 7% |
| 80s | 2 | 2% |
| Missing | 3 | 2% |
| Total | 121 | 100% |

Across the 121 participants in the pilot these represented a minimum of 353 household members. It is unclear from the data if the sample double counts household members. This provides an average household size of 2.9 individuals per household. This is within the range of what is a usual average size household within the Gypsy and Traveller communities. However, this hides a range of household sizes from one person to 13 people. The median and the mode household size is 2 people.

The sexual orientation of the participants was mainly straight (107: 88%) with only one participant identifying as bisexual, there were a total of 13 participants for which data is missing. There is very little information on faith background of the participants with only one participant stating their faith, this person reported themselves as Catholic.

## Location and accommodation type of the participants

As shown in Table 3 residents on local authority sites made up the largest section of those consulted with 53 (44%) engagements. This was followed by those living in bricks and mortar (28: 23%), private sites (21: 17%), roadside (7: 6%) and unauthorised sites (5: 4%).

**Table 3. Accommodation type occupied by participants**

| Accommodation type | Number | % |
|---|---|---|
| Local authority site | 53 | 44% |
| Bricks and mortar | 28 | 23% |
| Private site | 21 | 17% |
| Unknown | 3 | 2% |
| Roadside | 7 | 6% |
| Unauthorised site | 5 | 4% |
| Other (example transit site, holiday park) | 4 | 3% |
| Total | 121 | 100% |

Contact with participants were made across 17 independent locations as noted on the outreach log this are shown in Table 4 below. Locations and sites have been anonymised to remove the chance of identifying individual households. In some cases all households in one location/on one site took part. The vast majority of the engagements were located within a single large conurbation (47: 39%) followed by a modest to small number in a further 16 locations.

**Table 4. Location of the interviews by accommodation type**

| Location | Number | % | Accommodation type |
|---|---|---|---|
| Location 1 | 47 | 39% | Michaels Way Authorised Site (18), Bricks and mortar (15), Roadside (7), Unauthorised site (5), Other (2) |
| Location 2 | 13 | 11% | Private site (7), Bricks and mortar (6) |
| Location 3 | 10 | 8% | Local authority site (all) |
| Location 4 | 9 | 7% | Private site (all) |
| Location 5 | 9 | 7% | Local authority site (all) |
| Location 6 | 8 | 7% | Local authority site (all) |
| Location 7 | 7 | 6% | Local authority site (all) |
| Location 8 | 5 | 4% | Bricks and mortar (all) |
| Location 9 | 2 | 2% | Private site (all) |
| Location 10 | 2 | 2% | Holiday park (all) |
| Location 11 | 2 | 2% | Transit site (all) |
| Location 12 | 2 | 2% | Private site (all) |
| Location 13 | 1 | 1% | Bricks and mortar |
| Location 14 | 1 | 1% | Unknown |
| Location 15 | 1 | 1% | Local authority site |
| Location 16 | 1 | 1% | Unknown |
| Location 17 | 1 | 1% | Bricks and mortar |
| Total | 121 | 100% | |

## Health issues

Participants were asked if their lives and day to day activities were currently limited due to a health issue or concern. A total of 33 (27%) participants reported health conditions with 30 (25%) reporting no health concern. There was no information relating to 58 participants, the lack

of information may also be interpreted as an absence of a health condition. The health conditions that were mentioned were varied and included:

- mental health, mentioned on 7 occasions
- Chronic obstructive pulmonary disease (COPD), mentioned on 4 occasions
- arthritis, mentioned on 3 occasions

Other conditions included: heart attack, HIV, fibromyalgia, back problems, mobility, diabetes, incontinence.

### Caring responsibilities

Twenty-one participants (17%) reported having caring responsibilities or being cared for. Of these their responsibilities were for their children, in most cases, their husband or their parents. On 3 occasions the participant themselves were cared for by someone else.

## Experience of COVID-19 and associated practices

### Experience of COVID-19

Participants were asked if they, in their opinion, have had COVID-19 prior to the engagement. A total of 33 (27%) participants reported that they felt they had had COVID-19 at some point, a majority (70 participants/58%) reported that they thought they had not had COVID-19 with 18 participants either not knowing or not providing a response. In terms of their symptoms or experiences a number of events were recorded including: loss of taste, depression, feeling sick, flu like symptoms, sore throat, coughing, sweating, tiredness, high temperature, tight or sore chest. Only one person reported visiting hospital as a result.

### Experience of isolation

Participants were asked if they were currently isolating at the time of the pilot. Eleven participants (9%) were actively isolating at the time of the study.

### Experience of testing for COVID-19

Participants were asked about whether they were regularly testing. A total of 65 participants (54%) reported they were regularly testing, 39 (32%) said they were not regularly testing. There was missing data for 17 cases.

### Experience of the vaccination programme

Participants were asked if they had participated in the vaccination programme. A total of 59 (49%) participants had a single vaccination of those 48 (48%) had had a second dose with 4 having had a booster. At the time of interview 53 (44%) people had not had their first vaccination (see Table 5).

**Table 5. Engagement with the vaccination programme at the time of the interview**

| | Vaccine 1 | % | Vaccine 2 | % | Booster | % |
|---|---|---|---|---|---|---|
| Yes | 59 | 49% | 48 | 49% | 4 | 3% |
| No | 53 | 44% | 64 | 44% | 34 | 28% |
| NA | 9 | 7% | 9 | 7% | 83 | 69% |
| Total | 121 | 100% | 121 | 100% | 121 | 100% |

Whereas there was very little contextual information provided about their experience of the vaccine programme. A small handful of participants (4 cases) indicated that they would not have the Booster or reported that they were waiting (2 cases).

## Barriers to accepting the vaccine

Those participants who had not yet had the vaccine were asked about what barriers they saw stopping them. From the participants who provided a reason (n=36) there were a variety of responses (see Table 6 below).

**Table 6. Barriers to not having the vaccine**

| Reasons | Number of mentions |
|---|---|
| Does not want it or is not interested | 6 |
| Anti-vax | 5 |
| Regular movement | 5 |
| Lack of trust in the vaccine | 3 |
| Undecided | 3 |
| Due to be evicted | 2 |
| Parents ill after having the vaccine | 1 |
| Stopping after one vaccine | 1 |
| Waiting to have it done | 1 |
| Scared of needles | 1 |
| Memory loss | 1 |

Participants were given the opportunity to expand on any assumptions they held about the vaccine and vaccination programme. Again, this yielded a variety of responses. A large number of people said they had no assumptions at all. A large number of people further stated that there were ‘anti-vax’ – with the COVID-19 vaccine as well as other vaccines - or that they ‘didn’t trust

the government'. In terms of other comments, others suggested that there was 'not enough research' or that it was not 'FDA approved'.

A notable number, although modest in size, said that there were managing their personal COVID-19 experience through social distancing and remaining within their bubble so they did not need the vaccination. Some did state that they were open to changing their mind about the vaccine over time. At least 2 participants reported that they thought the vaccine made them ill and this would prevent them from being able to work or undertake their caring responsibilities. From speaking to project workers, further reasons were provided which included the notion of not trusting the government because of long-standing state-led discriminatory approaches towards the Gypsy and Traveller communities, both in the UK through exclusionary policies and reference was also made to the treatment of Gypsies during the Second World War.

Project workers also spoke about conversations with households who recounted the practical challenges of accessing drive-through testing sites when they only possessed a larger vehicle. This was a challenge in rural areas where households were commonly sited and where 'walk-in' sites were not provided.

Following on from these engagements the project team drew on what they learned about the barriers and concerns from members of the communities and produced an information video. This consisted of a panel of Gypsy and Traveller community members asking a GP some of the key questions members of the communities had given them.[1] This subsequently led to a series of videos that have been in production on similar themes. Whilst a deviation from the initial conceptualisation of how the pilot would be delivered this video has been regarded, by the project team, as hugely influential in sharing information with and amongst the communities. It should be noted that the project team did commend the use of mobile testing and vaccination facilities which came onto local authority sites and which saw significant use by residents.

## Knowledge about COVID-19 testing process

Participants were asked to rate their knowledge of the COVID-19 testing process on a scale from 1 to 5 (1 not at all knowledgeable, 2 not very knowledgeable, 3, moderately knowledgeable, 4 very knowledgeable, 5 completely knowledgeable).

The average knowledge score across the participants was 2.8 which implies that the participants on a whole thought they were moderately knowledgeable about the COVID-19 testing process prior to their engagement by the outreach team.

# Implementation

Members of the project team were asked about the implementation of the pilot. There was consensus across the team that due to the need to mobilise quickly that this led to some

[1] 'Gypsies and Travellers get answers to questions about the COVID-19 vaccine' (YouTube video)

implementation issues. For instance, there was a view expressed that the methodology for the pilot was developed quickly, with limited time for engagement from outreach specialists within FFT which led to some operational challenges through the project. Similarly, there was a challenge of capacity within the team, as a result of staff personnel changes, and the significant level of need of FFT's service users during this period, which sometimes contributed to challenges in responsiveness from the FFT local team. As an example, to address lone working challenges, 2 paid members of staff tended to visit sites which absorbed significant capacity. Instead, it was suggested, as a way to spread capacity, that these site visits could have been undertaken with a volunteer chaperone with a paid worker leading the visit.

In spite of these challenges there was consensus across the project team that the service provided to members of the Gypsy and Traveller communities as a result of the pilot filled a significant gap the communities had regarding COVID-19.

One member of the team reported that households were contacting FFT for information, not necessarily because they had been visited previously, but because they knew FFT and were a trusted organisation or the household had heard through word of mouth of the service being offered within the pilot. It was thought that the resources provided by the pilot were instrumental in addressing the needs households had.

## Information provided by the pilot team

As part of the engagement with participants a series of information and resources were provided by the outreach workers. This included a flyer which described the service on offer through the pilot and key messages about COVID-19, a lateral flow test box, a PCR test, information on using testing, and information relating to the guidance on self-isolation. This data is shown in Table 7.

**Table 7. Information and resources provided to participants**

| | Provided | % | Not provided | % | Missing data | % | Total | % |
|---|---|---|---|---|---|---|---|---|
| Flyer | 67 | 55% | 38 | 31% | 16 | 13% | 121 | 100% |
| LFT test | 82 | 68% | 36 | 30% | 3 | 2% | 121 | 100% |
| PCR test | 26 | 21% | 86 | 71% | 9 | 7% | 121 | 100% |
| Information on using testing | 51 | 42% | 59 | 49% | 11 | 9% | 121 | 100% |
| Information on self-isolation guidance | 52 | 43% | 57 | 47% | 12 | 10% | 121 | 100% |

Moreover, there was a sense that the visits to households played a wider educational role as the workers would often undertake physical demonstrations of how to do an effective test. This was in particularly high-need as many of the households that were visited had members with

significant literacy barriers and the written information within the leaflet, and other similar resources, had the potential of further marginalising members of the community. It was felt that the ability of the project team to physically demonstrate aspects of the information was transformational to some families.

Similarly, the outreach was seen as particularly important as access to the internet and television was not universal amongst the households being contacted so more proactive engagement with households was often a crucial way to communicate the messages.

FFT maintained, and continue to maintain, a web presence for the pilot. This also led to the establishment of a closed Facebook group for people to ask questions and share their experience. This was seen, by members of the project team, to serve a vital form of peer-to-peer learning within the communities.

### Support provided by the outreach team

As part of the engagement process the outreach team provided support, where it was needed and accepted, to participants. Support was provided on 11 occasions. In most occasions this took the form of a shopping or supermarket voucher or support to access or pay for gas.

From engaging with the project team the level of support provided, when needed by members of the community could be very practical indeed when households were self-isolating. This included supplying gas and clean water to households who were unable to access mains supplies.

### Access to COVID-19 pass and NHS applications

Participants were asked about their ability to access key or relevant digital resources. Only 4 participants reported being able to access these resources. Two people reported relying on the paper card provided at their vaccination appointment. One person reported they did not have access to smart phone. One person said they were not interested in having digital access.

## Experiences and mechanisms

There was a high degree of outreach worked delivered by the project team in order to engage with Gypsy and Traveller households. The project team drew on their network of known sites and locations for families, they worked with local authority Gypsy and Traveller liaison staff to identify private sites and they reached out on an ad hoc basis for people who were staying on the roadside or in bricks and mortar housing. FFT also maintained a vibrant web presence which described the service on offer and provided information and contact details. This web presence continues to be maintained, albeit with less urgency than during the period of the pilot. A 7-day a week service was also provided which provided a breadth of opportunity for families to contact the project team. However, it should be noted that it is the recollection of the project team that no one contacted the team on a weekend.

## Follow-up post engagement

From the entire sample of participants only 14 people appeared to consent to having a follow-up call or visit with the outreach team. It is not clear from the data recorded the outcome of these follow-ups.

When the project team were asked about the engagement with households regarding follow-ups it was recognised that households routinely did not want to be continually engaged in discussions about COVID-19 due to fatigue with the issue.

The project team reported that there was not enough time left to contact those who had been visited to engage in a post-visit follow up as the team's focus was on ensuring they reached as many households as possible with information and resources.

## Behaviour following engagements

As there is little information available, and a lack of consent for further engagement with households, it is impossible to provide objective and definitive information on how effective the engagements were. However, the feedback from the project team was that they were confident that the testing resources provided were being used with consistency and self-isolation procedures were being followed. Indeed, in terms of self-isolation one of the project workers recounted conversations they had had with households who expressed a willingness to comply with the guidance due to concerns they had over transmission to older, perhaps frailer and/or vulnerable, members of their families.

# Impact

The project team strongly asserted that the trust they had with members of the community, grounded in the reputation of FFT, provided the conditions necessary for the pilot to be as successful as it was possible to be within the short timeframe. A key factor in this was the ability to understand the lived experience of Gypsies and Travellers living under COVID-19 and the ability for workers to be approachable and empathetic. These were seen by project team workers as critical factors when working with members of Gypsy and Traveller populations.

A range of unanticipated outcomes from the work of the pilot are worth noting. These include the development of videos which help disseminate key information about health concerns in an accessible format on a YouTube channel to members of the communities. FFT have joined health focused networks within the area, notably the Vaccine Group with Brighton and Hove Council and other key stakeholders. Membership of this group has been helping shape the understanding of organisations about the issues faced by members of the Gypsy and Traveller communities regarding the COVID-19 vaccine and a wealth of other health-related concerns.

The specific outreach activities funded by the pilot project was seen to enable engagement with a larger number of households than would usually be the case. This has reported to have led to

an increased number of households engaging with FFT and an increased number of households engaging on health-related issues and concerns more broadly.

# Conclusions

It is difficult to draw definitive conclusions about whether the project delivered on its original aims.

The data recorded is not sophisticated enough to capture the proportion to which the outreach service was successful in improving access to and uptake of testing and self-isolation within Gypsy, Traveller and nomadic communities. Without adequate baseline data or measurable post-intervention data, due largely to the withholding of consent to be re-consulted, it is not clear – at the statistical level – whether any uptake in testing of adherence to self-isolation can be attributed to the pilot. However, drawing on discussions with members of the project team it is highly likely that the outreach activities were successful in demystifying these processes and guidelines. As a result, it is highly likely that the pilot had a material positive impact on testing and self-isolation, and awareness raising more broadly, amongst members of the Gypsy and Traveller communities.

The vast majority of those who were engaged with reported no or few barriers to testing and self-isolation. Of those who did report barriers issues such as a lack of trust in the government and the vaccine are noteworthy. In recognition of these barriers the steps taken by FFT to demonstrate testing processes and produce videos to answer and demystify these concerns were particularly powerful. FFT also engaged in a series of household-level demonstrations about testing and engaged a far-reaching social media presence about the service; this included a crucial peer-to-peer element. These non-text based approaches to working with the community were seen to have made particular inroads into improving uptake and access to testing and self-isolation.

There were some implementation challenges involved in the delivery largely around project set-up and operational capacity within the teams but these appear to have been managed without significant detriment to the project as a whole.

As a result of the pilot there were several other additional outcomes that are noteworthy. An increase in the number of households FFT are engaging with generally, the engagement of FFT with other providers in public health issues relevant to the communities, an increase in households approaching FFT regarding their health concerns, and innovations in the use of multimedia and social media

# About the UK Health Security Agency

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