FRIENDS, FAMILIES & TRAVELLERS

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Towards Zero: Gypsy and Traveller insights on sexual health and HIV prevention in West Sussex

Report compiled by:
Friends, Families and Travellers

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Introduction

Friends, Families and Travellers (FFT) is a leading national charity that works to end racism and discrimination against Gypsy, Roma and Traveller people and to protect the right to pursue a nomadic way of life. We support individuals and families with a range of issues that matter most to them, at the same time as working to effect change in systems and institutions to address the root causes of inequalities faced by Gypsy, Roma and Traveller people.

We work at a national and local level to challenge health inequalities and address the wider social determinants of health which put Gypsy, Roma and Traveller communities at high risk of poor physical and mental health. We do this both independently and in collaboration with the NHS and UK Government. As well as various partnership organisations, FFT develops and identifies evidence-based interventions to address health inequalities in Gypsy, Roma and Traveller communities. We work to amplify the voices of community members and equip people with the information they need to make healthy choices.

NHS England have specifically highlighted Gypsy, Roma, and Traveller communities as 'inclusion health' groups, which recognises the widespread social exclusion and typical "multiple overlapping risk factors for poor health, such as poverty, violence and complex trauma." There are significant health inequalities faced by Gypsies and Travellers leading to poor outcomes across the spectrum of health, with the poorest health outcomes of any ethnic groups in the United Kingdom. As a result, there is a much higher prevalence of disabilities and long-term illness, and life expectancies significantly shorter than the general population.

'Gypsy, Roma and Traveller' commonly refers to complex population groups made up of Romany Gypsies, Welsh Gypsies, Roma, Irish Travellers, Scottish Gypsy/Travellers, Showmen, Bargees, Liveaboard Boaters, New Travellers and Van Dwellers. It is important to understand that these are distinct communities, with distinct needs, histories, and cultures, and are afforded different legal rights.

Approach

This report explores how to increase HIV awareness and prevention amongst Romany Gypsy and Irish Traveller communities in West Sussex. Due to sex and relatedly sexual health considered taboo across many communities, the methodology included conducting qualitative research on individuals' knowledge and attitudes towards HIV prevention. During the question writing process, community members were consulted on the language, content and how to approach the subject of sexual health. Advice included using words such as 'protection' instead of 'condoms' and using 'sleeping with people' instead of 'sex'. Notably, questions were asked questions in the third person where possible, (e.g. *How do you think Travellers view…*) This ensured questions did not feel too invasive and helped ensure interviewees were as comfortable as possible when discussing a stigmatised topic.

Ten semi-structured qualitative interviews (lasting roughly an hour each) took place, and then a thematic analysis was used to identify common themes around barriers to testing and HIV awareness, what is going well, and any recommendations on ways of encouraging more discussions and testing amongst Romany Gypsies and Irish Travellers.

All ten people surveyed advised that sexual health promotion or offers of testing would not be appropriate at an FFT event or during outreach–concerns of potential reputational damage further justified the focus on research. The interviews revealed a possible route for sexual health promotion and awareness raising is via the facilitation of female-only groups, should this project continue.

Interviewee Demographics

Gender: 1 Male, 9 Female
Accommodation type: 4 on a permanent local authority site; 2 in temporary accommodation; 4 in bricks and mortar Council/Housing Association
Ethnicity: 6 Romany Gypsies, 4 Irish Travellers
Age range: 25-46

A note on demographics

These interviews are overwhelmingly female and do not include anyone living roadside, New Travellers, Roma, Boaters, Showman or any wider 'Traveller' demographic. This was partly due to 'convenience sampling'–people who took part were either close to the organisation in a professional capacity or who would be comfortable talking about a sensitive topic. With more time, more due consideration could be given to the demographics currently missing from this study.

Experience of participating in this project

This is FFT's first project of this kind centring around sexual health and HIV. Community engagement and outreach on this issue was not something easily explored when considering traditional values, sensitivity and stigma. Although the resounding feedback from community members was a desire for privacy and that testing or raising awareness at an FFT event would not be appropriate, there was also incredible honesty around a topic that is oft-exclaimed 'shameful'. It is worth noting male and female participants' willingness to talk about this with the main researcher, (despite interviewees receiving the offer to speak with a researcher of the same gender identity). This highlights the trust clients have in FFT and how willing people are to talk about these issues with the right person (who all agreed was primarily their GP).

As noted in the demographics section, 9 out of 10 interviewees were female. The female interviewees advised they would like a female only space to hold discussions around sexual health as well as: cervical screening, periods, checking your body for lumps and contraception. There was a lot of feedback from the interviews advising that FFT should facilitate this female only group to accommodate this need. There are often significant distinctions and hierarchies between different generations, therefore, a recommendation would be that a group is set up for younger women aged 16-25, women aged 25-45, and a group for elders (45+). Further funding is recommended to assess the feasibility of setting these groups up and gauging more widely, the want for them.

Further research should explore the experiences and attitudes of Traveller men, as these were lacking in these interviews. The only male in this research was the only person who had attended a clinic to be tested for Sexually Transmitted Infections (STIs). This reflected the widely-held view that a man attending a clinic, although still 'shameful' and 'embarrassing', has less to lose because it is more socially

acceptable for him to ‘sleep around’. Any additional research should address the extent this perception is expressed by Traveller men and how this affects their knowledge around sexual health and their likelihood and regularity of testing.

Barriers

The stigma surrounding sex and sexual health

The consistent theme that ran through all responses was shame and stigma surrounding sex outside of marriage and relatedly, sexual health. All people surveyed pointed to cultural identities and ideals contributed to stigmatisation. Many used words such as ‘dirty’ or ‘unclean’ to describe how respective communities might think of them if they were to be seen at a sexual health clinic.

“If you were seen someone would assume you were sleeping around…it’s all very embarrassing to go somewhere like that and get [testing] done.”

One respondent gave an example of this entering the sexual health clinic weekly for therapy as NHS therapy services were based out of a room at the clinic. Despite not actually attending the clinic itself, there was distinct discomfort as people *might* think they were attending.

“I used to get a lot of shame going there…it was pretty embarrassing”

How gender plays a role in sex stigma

Amongst all those surveyed, was the implication that women are expected to adhere to a strict ‘no sex before marriage’ rule and there would likely be shaming towards any sexual behaviour outside of a marriage for women:

“The women in Travelling communities are supposed to be pure before marriage”

Several interviewees made clear that there would be consequences if their community thought a woman had been to a sexual health clinic, including social isolation and accusations of being unfaithful. As Travelling communities are often tightly bonded and community-oriented, this would be exceptionally detrimental to an individual:

"No one wants any talk about it, no one wants any show up, no one wants any, what do you call it, like dishonour on the family"

It was acknowledged that men do not experience this social pressure to the same extent. However, the male interviewee talked about the presence of 'shame' towards men in the communities if they do have sex before marriage, with the shame coming from the community because of the assumption of sleeping with someone *outside* the community, which is looked down upon:

"For men…it's like you've went outside of the community…so they tend to keep it private if they've went for [sexual health testing]."

Another observation made by our interviewees is that because men avoid the worst of the stigma around sex and sexual health, it is a man's responsibility to engage in STI prevention for himself and his wife/partner. All who made this point were female; they felt that because they were expected to only have one partner and would receive more backlash for attending a sexual health clinic, men should make sure they are 'clean' for them. This presents a barrier, especially because there was no mention of the women having these conversations with their husbands, just the inference that the men should already know this:

"Now obviously women are a lot safer than men, there's a cultural thing where women have only had one husband but it's the men…that need to address this."

"I shouldn't have to think about it as I've only ever been with one person."

Reluctance towards preventative forms of medicine

"They would wait until they got symptoms, they wouldn't randomly go and get tested."

The majority of interviewees commented that Gypsies and Travellers would only seek out an STI test if they had symptoms. When asked whether they had attended clinics before, two respondents said they hadn't for themselves but provided anecdotes of partners or friends who had had symptoms of other STIs, and they had accompanied them to the clinic. Present day HIV prevention methods encourage regular testing rather than being led by symptoms. HIV symptoms are not universal;

the most common is a flu-like illness and after this, some may not experience any symptoms for many years. This is consistent with some travelling groups' approach to other preventative medicine, such as immunisations. For communities who have faced chronic exclusion and discrimination in medical systems, it is unsurprising that there would be wariness and hesitation to engage in treatment or testing when there is seemingly nothing wrong.

Knowledge of Prep

Out of ten surveyed, one knew about preventative medications for HIV like Pre-Exposure Prophylaxis (PrEP).

Amongst most respondents there was a general positive attitude towards PrEP and a good understanding of why it's effective. However, all surveyed believed that there would be little to no uptake of PrEP by Gypsy and Traveller people, and there was a resounding feeling that it is not something that is 'for them':

"If people can take things to stop them getting things, good luck to the people."

The reasons were similar to why many wouldn't take a HIV test:

"The community we come from, there is no sex until we get married. So, [taking Prep] doesn't register with them."

Access to sexual health clinics

One interviewee mentioned that they were offered a sexual health appointment in Crawley, which is roughly 30 miles from their home in Lancing. This has been presented as another reason for the preference of attending a local GP surgery.

Several pointed to a further barrier this would present an individual if they could not drive, especially in the more rural parts of West Sussex:

"I had to go to Crawley to get my implant put in in May…What if you couldn't drive? I'm lucky that I can but it would be a lot harder."

Another barrier to accessing clinics is wait times, with several interviewees experiencing a wait between 4-6 weeks for an appointment. They acknowledged this was to have contraception fitted and not for an STI test, but suggested that this is a

huge barrier for individuals who, *"already feel anxious and worried about being judged for going to a sexual health clinic".*

Privacy is paramount

When discussing home testing, several interviewees commented that a home test would not be private enough if you are living with people who you don't want to know you are testing. Some advised it could cause conflict between partners and may cause people to assume they have been unfaithful to them:

"In a lot of Traveller homes, it would cause a lot of uproar and rows and arguments."

Similarly, every single interviewee highlighted the problem with sexual health clinics; that you risk seeing someone you know there:

'If we were seen going there someone might think 'she's got something bad'."

Instead, the majority of respondents pointed to the GP as the primary location they would want to discuss sexual health and get tested. This is because it is considered the most private and discreet place for sexual health matters. This presents a further barrier due to the postcode lottery whereby some GPs will do STI testing and some will not. From anecdotal evidence many West Sussex GPs will not offer testing and instead signpost to the nearest sexual health clinic.

Views on sex education at school

Another barrier is communities not having a foundational knowledge around sexual health, which stems from educational inequalities present in the schooling system.

Gypsy, Roma and Traveller communities often face a myriad of barriers in education such as; discrimination, bullying (from teachers and students), problems maintaining education whilst travelling, disproportionate rates of expulsion, and a lack of cultural representation in the curriculum. As a result, drop-out rates for children from these communities are much higher than the general population. This may lead to some children receiving much less sex education, or none at all.

Additionally, some parents feel that sex education at school is being taught too early or should not be taught at all. Several interviewees expressed concern around this, specifically that sex education is taught at primary school and that topics like sexual

pleasure are being discussed with their children. This concern has also been raised by people calling FFT's national helpline and anecdotally, this is considered an additional factor in a parent's decision to remove their child from school. As school is already a site of anxiety for Gypsy and Traveller parents, concerns around what schools are teaching and at what age, only intensifies these anxieties and mistrust:

'My sister had told the school she didn't want her [daughter] doing the sexual health lesson, she was only young at primary school. She was meant to be taken out the class, but the nurse made her stay in the class. I went in and spoke to them.'

What's Working?

Awareness of sexual health

Every person surveyed could name at least two sexually transmitted diseases and the majority knew how someone can protect themselves from them. Five out of six interviewees named HIV:

"Get check-ups, use certain protection [condoms]."

Most people interviewed suggested that knowledge around STIs and prevention methods are more widespread than people may assume however, the stigma and shame (especially towards women) stops regular testing and information being disseminated through the communities:

"Most Travellers are aware [of sexual health and testing] but are too ashamed to let anyone else know that you know."

Overwhelmingly, interviewees had a good understanding of what HIV is and that using condoms ('*protection*') was an effective method of prevention. Many also discussed the misinformation that was widespread about HIV/AIDS during the 1980s and 1990s and knew that these myths were not true:

"Obviously, you can't really catch AIDs through a cup."

"It's a big misconception that it's only a 'gay disease' but that's something I used to believe as a kid."

Changing perspectives on sex and sexual health

The majority of interviewees commented on the changing attitudes to sex and sexual health in their respective communities. Many expressed that they are much more open about these topics with their children than their parents ever were with them, signalling an important cultural shift. Several referred to the fact that the 'birds and the bees' chat is seen as much more important for young people now due to changing cultural norms, like young boys and girls mixing much more, and the impact of the internet:

"I was never allowed to learn about sex education at school, but I want my daughter to be aware of things I wasn't at school, but at an age-appropriate age."

Testing during pregnancy

Seven out of the nine women interviewed had been tested for HIV when they were pregnant (1 did home test and 6 tested at a hospital). For all the women, this was the only time they had been tested for STIs. Four reported that they hadn't had this done for their first child but were tested when having subsequent children, signalling that perhaps this is becoming common practice for pre-natal care.

What is needed?

The majority of respondents cited being able to get STI tests at the GP surgery as important in removing barriers for Gypsy and Traveller communities. They stated that the privacy felt going to a GP rather than a sexual health clinic was enormously important, which helped remove the stigma and shame of getting tested.

The majority of interviewees described how they trusted GPs the most and this would help people feel safe going to get tested and having conversations about sexual health. This is consistent with FFT's clients' anecdotal accounts of who they trust in the medical system, especially amongst the older generations. Many have had the same GPs for several years and regard them as a trusted professional.

Previous FFT-facilitated focus groups on health have also highlighted the GP as a primary source of medical information, although, involvement from women in focus groups tends to be higher (as in this study) and, overall FFT provides more advocacy

for women than men in the communities. Therefore, the preference for GPs doing STI testing may only be applicable to women:

"I think many Travellers would prefer a GP [to do STI testing] as there's no obvious way of telling what you're doing, it's more private."

Recommendations

- There is a clear need for more messaging that informs people that partners may have been transmitted an STI like HIV from *previous* partners, alongside an emphasis that testing and diagnosis does not mean unfaithfulness. Several people advised they trusted their partners and had been with them for a long time so did not feel the need to test:
    - *"The only way to address this is the message: it could have been spread before you got with your partner."*

- Additional messaging that posits testing as important for pregnant women to protect their children from diseases like HIV is vital. A respondent described being upset being asked to test when she was pregnant:
    - *"I was embarrassed having to do it [a home test STI kit] at my mum's house…I was upset I had already explained to them that I hadn't been with anyone else. I had a little chat with mum, she said [do the test] to keep the baby safe."*

- There is a need to platform people with lived experience of HIV to raise awareness and tackle the stigma, as feedback has shown that these stories are memorable and powerful.

- HIV tests should be included in routine blood tests that GP surgeries do:
    - "*That's the only way you're going to get it done, it's discreet, it's private".*

- Ensure GP surgeries ask about sexual health testing in cervical screening appointments, blood tests, and other forms of patient contact.

- Regular communication, similar to cervical screening reminders, should be used to encourage people to book a test in. For people with low literacy levels or other learning needs, these letters should be in easy-read language, along with a QR code to a video about STI prevention. Special consideration should be given to language, such as inviting people for a 'health check':

    - *"Doctors should send out letters. The same way you have your smear done. When youngsters get to a certain age. They should promote it as*

a 'health check', a routine check every couple of years…Or the pharmacy could do it. Just make sure people know it's for everyone so no one is being targeted."

- Special care should be taken to provide female-only spaces to discuss sensitive issues, run by community organisations, such as FFT.

- There is a widespread need for schools to be transparent and collaborative about what is taught in sex education. This can help parents feel more comfortable and ensures children are taught the fundamentals of sexual health. Some practical suggestions to aid this:
    - Send the relevant syllabus to parents;
    - Meet with parents and talk through anxieties;
    - Organise gender-specific classes (majority of study respondents showed preference for this, due to norms around separation of genders).

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. **www.gypsy-traveller.org**

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