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Improving Hepatitis Awareness and Access for Gypsy, Roma and Traveller Communities

Compiled by
Friends, Families and Travellers

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Acknowledgements

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About us

This insight was conducted by Friends, Families and Travellers (FFT) and Roma Support Group (RSG).

FFT is a leading national charity working to end racism and discrimination against Gypsy, Roma and Traveller people and to protect the right to pursue a nomadic way of life. We provide practical support to individuals and families facing issues such as insecure accommodation, barriers to healthcare, financial and digital exclusion, and discrimination in education. We also work to address the root causes of inequality through policy, advocacy and system change. Each year, we deliver over 4,300 advice sessions and support more than 1,300 people through phone, online and in-person services.

RSG is a Roma-led charity based in East London that works to improve the lives of Roma refugees and migrants by tackling prejudice, isolation and vulnerability. RSG supports around 2,000 Roma people each year through services including welfare advice, health support (including mental health), education, financial inclusion, housing, policy work and cultural activities. Around 120 people receive one-to-one health advocacy annually. Since 1998, they have worked with thousands of Roma families, involving the community in running the organisation and promoting understanding of Roma culture in the UK.

‘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.

Executive summary

This report presents findings and recommendations on healthcare access, blood-borne hepatitis awareness, stigma, and barriers to engaging with health services among Gypsy, Roma and Traveller communities.

Access is limited by inflexible systems, stigma, privacy concerns, and gaps in hepatitis knowledge. Mistrust of statutory services and fear of judgement further discourage people from seeking support. Engagement improves where approaches are flexible, confidential, and delivered through trusted organisations, and testing uptake increases when services do not require GP registration and are offered as part of wider health checks.

Introduction

Gypsy, Roma and Traveller communities experience some of the most severe health inequalities in England.[1] Evidence consistently shows poorer health outcomes, higher levels of long-term illness[2], and reduced life expectancy compared to the wider population.[3] These disparities arise from structural disadvantage, discrimination, and barriers within healthcare systems.

Barriers include wrongful refusal of GP registration, digital exclusion, inaccessible health information, and services that do not accommodate nomadic ways of living or cultural norms[4]. As a result, public health messaging does not consistently reach Gypsy, Roma, or Traveller communities, limiting awareness of health issues and access to information.

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* Minority ethnic group and therefore protected under Equality Act 2010.

[1] Parry, G., Van Cleemput, P., Peters, J., Walters, S., Thomas, K., & Cooper, C. (2007). Health status of Gypsies and Travellers in England. Journal of Epidemiology and Community Health, *61*(3), 198-204

[2] Office for National Statistics, '2011 Census analysis: What does the 2011 Census tell us about the characteristics of Gypsy or Irish travellers in England and Wales?'

[3] Office for National Statistics (ONS), released 13 October 2023, ONS website, article, Gypsy or Irish Traveller populations, England and Wales: Census 2021

[4] Friends, Families and Travellers. (2023). Test, treat and trace for Gypsy, Roma and Traveller communities

Our approach

This report draws on qualitative research, including ten semi-structured interviews (each approximately one hour) and three focus groups with people from a Romany Gypsy, Roma, or Traveller background.

Research questions were co-developed through a national steering group made up of community members, incorporating review of language and content, guiding sensitive topics, and offering valuable lived experiences to foster connection and relevance. Data was analysed thematically to identify barriers, explore knowledge, and inform recommendations for improving services, engagement, and support.

Demographics

Participant information	Details
Age range	28-65
Gender	8 female, 2 male
Background	2x New Traveller, 2x Irish Traveller, 2x Romany Gypsy, 1x Showman, 3x Roma
Accommodation	9 living in bricks-and-mortar, 1 roadside
Location	Birmingham, Kent, London, Sussex, Bristol

Findings

Theme 1: Access and practical barriers

- People living nomadically may experience barriers to accessing GP services and maintaining continuity of care. These barriers stem from the organisation of services rather than the absence of a fixed address, as registration should be possible.
- **Long waiting times** and **inflexible appointments** limit access. Walk-in clinics are sometimes the only option but they are often impractical, so care is delayed until problems become urgent or multiple issues arise.
- Cultural and family expectations, such as women attending appointments with chaperones or extra family members, can limit privacy and make it harder to discuss sensitive health issues.

- Literacy and language barriers may make it more difficult to understand key information, navigate online systems, or respond to letters, which can impact access to appointments and follow-up care.

“Women couldn’t just go alone, they’d need a family member with them. And for things like sexual health before marriage, it was really hard to talk to the GP because someone else would be there.”

“When I was younger and we were roadside, we weren’t registered anywhere and were often told to just go to a walk-in centre, which wasn’t always nearby and we couldn’t leave all the stuff on the fairground. We had to wait until we got back to our main site to see a doctor.”

“I struggle with using internet and writing, it’s hard to explain why I need appointment, it’s really depressing.”

Theme 2: Stigma and privacy

- Concerns about confidentiality and data privacy can discourage meaningful engagement with health services.
- Fear of negative consequences can affect decisions about accessing care, including concerns about family reputation, marriage prospects, social services involvement, and judgement.
- Past experiences of judgement within healthcare settings contribute to ongoing mistrust of mainstream services; positive experiences are rare and usually depend on individual staff rather than consistent system-wide practice.
- Gender norms affect engagement, with older men often avoiding routine care due to pride, embarrassment, or fear of ‘appearing weak’, while younger people and women are more likely to attend appointments.
- Reliance on family members for interpretation can limit privacy and make it more difficult to discuss sensitive or stigmatised health issues.

“Sometimes it is embarrassing to speak about some of my health problems in front of family member, it would be easier with interpreter.”

“Many Traveller families are scared of social services.”

"Too much dignity, pride comes first. My father-in-law won't go to the doctors, he refused. I had to force him in, I started crying to him and this worried him. It's important to me, I lost my dad at 47."

Theme 3: Knowledge gaps and misinformation

- Many were unaware that hepatitis C is curable, hepatitis B is vaccine-preventable, or that infection can be asymptomatic, reducing perceived need for testing.
- Misconceptions about causes, transmission, and symptoms are common, including confusion with HIV.
- Knowledge is often based on lived experience rather than formal health messaging.
- Certain activities involving blood exposure, such as tattoos, sharing hair clippers or razors, and bare-knuckle boxing, may increase risk but are not always recognised or discussed.
- Misunderstandings about risk are common, with some wrongly assuming that being clean, healthy, or well-groomed is enough to prevent infection.

"In the Traveller community, risky stuff like tattoos and bare-knuckle boxing can spread it. There's also a wrong belief it spreads through dirty cups. People assume if you look clean and groomed, you're okay."

"People are worried, they do not know much, they think it's serious, but people do not know about testing and how to find out about hepatitis."

"Before my diagnosis I did not know anything. I am worried because my brother died because of similar illness. I was told I always have to take medication and I can't be cured."

Theme 4: Trusted sources and digital approaches

- Doctors and nurses are the most trusted sources of health information, even when trust in services overall is low.
- Older and respected figures, along with health champions, play a key role in sharing information and supporting engagement within communities.
- Online videos and social media are effective ways to share health information with people experiencing literacy barriers, particularly when the information features trusted health professionals.

- Messaging that focuses on wider health checks, delivered using trusted NHS guidance and branding and avoiding stigmatising labels such as "Hep C", can reduce stigma, build credibility, and encourage engagement.
- People often rely on home remedies, herbal treatments, and guidance from religious figures for health information.

"It would be good to have films with doctors specialising in hepatitis explaining what it is, how to get tested and treated."

"Some parents can't read, but the kids know how to use phones… they can tell their parents through TikTok, Facebook, or Instagram."

"Some try home remedies like herbal treatments or bleach, and some listen to advice from priests about being healthy."

Theme 5: Flexible, accessible, and inclusive services

- Services must have privacy, trustworthiness, and flexibility, with face-to-face appointments preferred over phone-only systems.
- Mobile health services are welcomed if private and flexible, while outreach directly onto sites can feel intrusive.
- Drop-in services outside work hours are preferred, particularly by men who may face stigma in taking time off.
- Clinics and drop-in services should take place in locations already frequented by community members, such as churches or community venues.

"Somewhere walkable. Somewhere you don't have to register with a doctor. Anonymous too."

"It would be good to have drop-in services in places most often visited by the community, for example town centres, shopping centres, churches, community events and venues."

"There's stigma around taking time off for appointments, and people can be accused of not providing for their family. Staff need to understand cultural barriers."

Recommendations for health commissioners, public health teams, integrated care boards, integrated care systems, local authorities, and primary care teams

- Enable supported access to primary care for people without a GP, reducing barriers to testing and ensuring treatment is accessible for nomadic communities.
- Offer flexible appointments, including walk-in or drop-in options in accessible locations.
- Provide same-gender clinicians where possible to support comfort and privacy, particularly for sensitive consultations.
- Provide all staff with training in inclusive service provision, non-judgemental practice, and trauma-informed care, with a focus on building trust. Include values, barriers to engagement, stigma, discrimination, and the realities of roadside and site-based living.
- Training should be provided on a regular basis, ideally biennially with staff maintaining up to date understanding of Gypsy, Roma and Traveller communities.
- Take the opportunity to offer testing when people present to services, to reduce missed opportunities and increase uptake.
- Consider models such as the Probation Neighbourhood Health Service pilot scheme, which uses multi-agency outreach to reach people facing health inequalities, as a way to improve access to hepatitis testing.

Recommendations for healthcare providers across the system, including voluntary, community and social enterprise organisations

- Use people’s preferred communication methods, including phone calls, WhatsApp, or voice notes, rather than relying only on letters or online portals.
- Deliver services in private, confidential, culturally sensitive settings. Offer anonymous or low-visibility options.
- Actively consider how to engage men, who are less likely to attend appointments. Use flexible timing, informal settings, and male-friendly outreach approaches.
- Provide clear, simple, and culturally relevant information on hepatitis, including symptoms, transmission, testing, and treatment. Ensure it is

respectfully framed, uses accessible language and formats (visual, audio, easy-to-read), and is delivered via trusted sources within the communities.

- Consider providing handheld paper records, particularly for people who travel, with the option to also add information to the NHS app.
- Offer for routine health checks to include testing, which helps to build familiarity and trust and can avoid problems becoming urgent.
- Recognise the diversity within Gypsy, Roma, and Traveller communities, tailoring services to cultural, gender, and way of life needs.
- Offer general health checks (e.g. eye tests or routine screening) rather than single-condition services to further reduce stigma.
- Use neutral, familiar public locations such as car parks or roadside cafés instead of Traveller sites, to maintain privacy.

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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