

Statistical bulletin

Gypsies' and Travellers' lived experiences, health, England and Wales: 2022

Qualitative research exploring the lived experiences of Gypsy and Traveller communities, relating to health.

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1. Other pages in this release

- Gypsies' and Travellers' lived experiences, overview, England and Wales: 2022
- Gypsies' and Travellers' lived experiences, culture and identities, England and Wales: 2022
- Gypsies' and Travellers' lived experiences, homes, England and Wales: 2022
- Gypsies' and Travellers' lived experiences, education and employment, England and Wales: 2022
- Gypsies' and Travellers' lived experience, justice, England and Wales: 2022
- Gypsies' and Travellers' lived experiences, methodology, England and Wales: 2022

2. Main points

- Participants described experiencing a range of health conditions, which, coupled with delayed healthcare seeking and perceived barriers to accessing healthcare, could create vulnerability to negative health outcomes among Gypsies and Travellers.
- Participants described environmental factors, such as site locations and living conditions as well as
 occupational hazards that they felt were linked to the health conditions they experienced.
- Challenges were described in registering with a GP surgery without a fixed address, particularly among those living in Gypsy and Traveller sites or roadside.
- Delayed access to healthcare could result in delayed diagnoses and treatment, and could undermine
 access to screening and preventative care, with potential negative health consequences.
- Experiences of perceived discrimination and derogatory attitudes of healthcare providers could further undermine access to healthcare, as participants had concerns about the likelihood of receiving help and feared facing negative judgement or discrimination.
- Familiarity, understanding and open communication with trusted health practitioners appeared to support access to and engagement with healthcare.

3. Managing health and seeking healthcare

Participants from Gypsy and Traveller communities described experiencing a range of health difficulties, including chronic obstructive pulmonary disease (COPD), asthma, diabetes, bladder problems, "the c-word" (cancer), and mental health difficulties. They believed many health conditions were caused by environmental factors, such as sites located in polluted areas with poor standards. Some also described experiencing work-related injuries or conditions.

My hands are constantly in agony. I can't put my hands up without them going dead... it's repetitive strain injury. Working out in the cold is what does us all in. It happens to a lot of Travellers. You push your body too far just for the sake of a few quid. That's one thing, but when you try and get the help you actually need, they are not interested.

Male, aged 30 to 40 years, local authority site

Views on the potential public health implications of poor site conditions, for example overcrowding, lack of available water and infectious disease outbreaks, were reinforced by local or central government participants.

Although participants described mental health challenges affecting Gypsies and Travellers, they suggested this topic is not widely spoken about within communities. Difficulties accessing mental healthcare were also mentioned. These partly linked to apprehension about seeking help and feeling misunderstood or treated unsympathetically by healthcare workers because of their ethnicity, and partly linked to difficulties asking for help at all.

I actually suffer with severe bad mental health problems. I was diagnosed with being bipolar back about 10 years ago. And I really can't get the help from the mental health team, I think it's the same again, because they've identified that I'm a Traveller, and can't be bothered with me.

Female, aged 40 to 50 years, bricks and mortar

Some participants described approaches to self-management of health symptoms through the use of home remedies. Although participants also described using the healthcare system, home remedies were said to have been used intergenerationally, particularly for managing minor ailments.

We have old medicine we have always used...I guess on the road you had to know how to look after yourself and your animals and we just learned it from our parents.

Female, aged 40 to 50 years, local authority site

Some described a belief that speaking about ill health or seeking healthcare could worsen health conditions, with participants largely speaking about accessing healthcare only when very unwell. Delayed health seeking was particularly described among men.

In our community it's not until... we're on our last legs or something... We drop dead or we should have got help... So even if you had loads of pain or something like that, you wouldn't go until it got to the point.

Community member, Focus Group 5

Additionally, women described requiring female health practitioners for certain health needs that, if unavailable, could further undermine seeking healthcare.

You can't go to a normal doctor that's the problem, because you say, well, if you've got problems that you need to talk to women about, you can't sit there and talk to a man about it. And then you're forced to talk to a man about it.... You say, 'well, I want to talk to a woman.' They're like, 'no, well, you have to go with somebody else.

Delayed presentation to healthcare services among Gypsies and Travellers was also recognised by local authority participants, who highlighted the importance of preventative approaches to healthcare as beneficial both in human terms and financial savings.

What we've learned is the earlier the intervention, the greater the saving. And often Gypsies and Travellers will present themselves at a very late stage of quite significant illness. Then the costing is far, far greater, could mean hospitalisation, may mean intensive care and actually this could have been nipped in the bud three years earlier and the cost savings would have been phenomenal. So, it makes financial sense even to do it as well as human sense.

Local authority participant, England

Health seeking experiences were not universal. Some participants described seeking healthcare earlier, accessing preventative care including cancer screening and antenatal care. Where reported, family encouragement to access healthcare, particularly from the younger generation, appeared to support engagement. Health seeking was also linked to access (see Section 4: Barriers to accessing healthcare).

I go straight to a doctor and straight into hospital. I don't, I try not to neglect myself, which I haven't done for the last 20 to 25 years. I've always kept my dentist appointments up every six months and go and have a full annual MOT over at the doctor's surgery every six months. Medications reviews, hospital appointments, X-rays yeah. I don't neglect myself anymore as far as my health's concerned.

Male, aged 50 to 60 years, local authority site

4. Barriers to accessing healthcare

Participants described barriers to accessing health services, particularly primary care services. This could undermine access to routine immunisations and preventative care, and result in delayed diagnoses and treatment, including regular or repeat treatment. Almost all community member participants described difficulties accessing a GP surgery without a fixed address, as part of their own experience or that of others around them. This appeared particularly challenging for those living roadside or on Gypsy and Traveller sites.

You wouldn't be accepted at the doctor's... because she didn't have a settled address. You couldn't say when I'm living on the side of the streets and trailers, we call the caravan as the settled community houses. We couldn't, you couldn't give that as an address. It wasn't acceptable. So... you couldn't register with the doctor when having to get seen.

Female, aged 70 to 80 years, bricks and mortar

Participants who worked for civil society organisations (CSO) described the option to register with a GP using the surgery's postcode. However, this did not appear to be widely known or to always enable GP access.

You couldn't get the GP and with the GPs here, they're told they have to use the postcode of the GPs. So, say like, you put your caravan on Smith Road... go to the GP you say I'm on Smith Road and they use their postcode, the doctor's postcode and then you're supposed to get medical treatment. That's what they're told to do.

Community member, Focus Group 5

Where participants did describe managing to access a GP with a site address, this seemed to be possible through the support of individual local authority staff or CSO support workers. However, additional challenges could be faced with navigating burdensome systems to retain access, including not being able to receive postal communications to site addresses, which could be required to remain registered and to receive health information.

... And told me that if I don't get back in touch with them, they are going to strike me off. They had never been in contact before. Yep.

Participant B, male, aged 30 to 40 years, local authority site

The perceived need for support from council staff to be able to access a GP surgery was also reinforced by local authority participants.

Some participants described feeling the need to move into settled accommodation to be able to access health services, for example moving into bricks and mortar, even if this went against individuals' broader preferences and cultural values (see Gypsies' and Travellers' lived experiences, homes, England and Wales: 2022 bulletin).

My wife started to take ill and for the best part of 16, 17 years she was really ill, and we had a job to get a doctor because we never stayed in one place long enough to register with the doctor, and we had difficulty. Then we bought this flat cheap, it's in a bit of a rundown area, but we bought it cheap. My brother-in-law loaned me half the money to buy it because we had to have somewhere settled.

Male, aged 80 to 90 years, bricks and mortar

Participants mentioned facing literacy barriers to engaging with health services and the increasing use of computer systems to access appointments as challenging for some.

[Some] Gypsy people can't read or write, do you know what I mean? So how are we meant to do like online stuff when we don't know how to do it and then access all that.

As a result of the challenges people described with accessing a GP surgery, many spoke about relying on accident and emergency services and walk-in clinics to access medical care, sometimes waiting several hours to be seen, or travelling long distances to access a trusted GP.

My own doctor is 100 miles from here... It's because of this address, it's blacklisted where I am right now, they won't take any patients on and I need to get my medication. My tablets, my repeat, I have to go down to [town], it's 100 miles to drive down to get my tablets.

Male, aged 20 to 30 years, transit site

People also spoke about experiencing barriers to emergency services and health visitors coming to sites, with several people describing delayed access to emergency services or experiences where ambulances would only visit sites with police escorts.

You can't get an ambulance, if you ask for an ambulance to come, they send out the police... there's a couple of stories where a gentleman, they knew of his illnesses, they knew he was quite unwell, and people called for an ambulance and the police come on and instead of the ambulance coming on. They held the ambulance off down the end road, it was just loads of police but by then, by the time the ambulance got to him it was too late.

Female, aged 40 to 50 years, local authority site (from field notes)

Described experiences with difficulties accessing GP surgeries and health visitors could also undermine access to preventative care and routine immunisations.

There used to be like a network of health visitors, and they have their own organisation that would go to Gypsy and Traveller sites and that lost all its funding before COVID. And that's a real big detriment...because a lot of the babies are missing their six-week check.

Community member, Focus Group 3

5. Trust in health services

Police presence when accessing emergency health services could be particularly challenging given the wider context of difficult relationships with the police (see Gypsies and Travellers lived experiences, justice, England and Wales: 2022 bulletin). Fear of police presence appeared to undermine trust, feelings of safety and engagement with health services.

When we had a gentleman having a heart attack, they needed a police presence to administer first aid. When they want to give us a vaccine, they don't need police presence.

Community member, Focus Group 1

Participants also described concerns around the potential for negative social judgements and the involvement of social services when accessing healthcare, with fears of children being taken into care as a result.

My daughter took her little boy... they went up to the hospital, her and her husband. They took the baby in [for routine check-up]. They took the blood, but he had a mark, where he fell, because he was crawling and getting to walk, was nothing, was nothing, nothing at all to worry about. He [doctor] kept him in overnight to get checked out, and said he has been abused... [now] they will not take the children to doctors or hospital. My daughter will not take the children. If I don't take them, they don't go because she's afraid they [will get] took off her. She's very, very worried.

6. Experiences of relationships with healthcare workers

Participants described experiencing some positive relationships with healthcare workers, which appeared to make a difference in supporting their access and engagement with health services. However, participants also described having experienced perceived discrimination and derogatory attitudes from healthcare providers, as well as anticipating discrimination based on others' experiences. Fear of discrimination and doubts about whether help would be offered from healthcare providers appeared to undermine access to healthcare.

When you're pushed like that your whole life, and you feel embarrassed at A&E, you don't present. So then when you have got like terminal cancer, you don't present to the point where you are terminal, you know, so the first point of contact is A&E and when it's at the point of no return, then this is the problem. If you're constantly embarrassed, then you just avoid it. You know, and this is the problem. You are constantly embarrassed by the NHS.

Community member, Focus Group 2

Challenges with accessing health services because of perceived derogatory attitudes were described relating to interactions with a range of health practitioners, and particularly mentioned in relation to GP surgery reception staff, who were perceived as gatekeepers to GP access.

One participant described not feeling able to see a doctor because of not being registered, having tried and been told "oh, you don't belong here, get out" (male, aged 80 to 90 years, bricks and mortar).

The receptionists, the attitudes of them is absolutely diabolical, there are some which never really ought to be receptionists at all. And on numerous occasions, I've spoke to a lot of Travellers, and they've had the same problem with that surgery and they've complained, put it in emails about the attitude of the receptionists.

Female, aged 40 to 50 years, local authority site (from field notes)

The view that reception staff can present barriers to accessing GP surgeries was reiterated by local authority participants.

Perceptions of differential treatment because of ethnicity were described, as well as communication barriers including misunderstanding and use of different terminology between health practitioners and community members. These were linked to delayed diagnosis.

I can't seem to get a doctor to listen to me.... my family have a history of suicide and it terrifies the living daylights out of me, and I remember driving down the road and for the briefest seconds I remember thinking 'oh my, I could just head to that tree and nobody would notice'.... I went to the doctor and explained to the doctor this momentary thought I had, it worried me because a lot of my family have committed suicide and it's always been like a completely off the cuff... It frightened me. And the doctor told me, [in] all seriousness like there wasn't a smirk on his face... 'I really don't think suicide's an option for you.' And I was like what, would you prescribe it for some people then?

Female, aged 30 to 40 years, bricks and mortar

Again, this was not universal, and some participants described experiences engaging with health services where they did not feel they were treated differently based on being a Gypsy or Traveller.

Thank God I've got five children they're all healthy but my oldest little girl she's poorly. She has a rare condition... thank God they've given the treatment and they found out what's wrong with her and this put me in the right direction. And they've been good to me, around here the healthcare and things. They haven't judged me because I'm a Traveller and things, they've helped me.

Female, aged 40 to 50 years, private site

Participants highlighted the difference good relationships with health practitioners made for their engagement with health services and the quality of care received. A good relationship included feeling listened to, understood, and respected by health practitioners.

Participants appreciated communication approaches that were receptive and accessible, including health practitioners offering clear explanations and listening to concerns. Relationships could be supported through familiarity over time, and some described travelling long distances for a trusted health practitioner.

He understood me. He understood me because he seen me grow up from when I was a child... straightaway he went through all the right letters and got me a referral and got me, but I was literally three weeks trying to get back to hospital and they won't listen.

Community member, Focus Group 1

Some felt that the quality of relationships with health practitioners had deteriorated over time, with less regular contact with a health practitioner undermining familiarity and trust-building.

And I think in this day and age, we have gone backwards instead of going forward because it is at the end of day, we used to have a one-on-one relationship and people [GPs] know you personally.

7. Towards solutions

Participants suggested possible solutions that could improve described difficulties with access to health services, such as accessible formats for delivering health information and appointment reminders, mobile outreach clinics visiting sites and people with lived experience linking community members to health services.

A number of times our welfare officer will sit and read letters to people about health, appointments and advertising more accessible formats for those who can't read and write. Just because someone's got a mobile phone doesn't mean they've got a smartphone. It's thinking again differently about this speech tech and promoting that as well.

Local authority participant, England

Additionally, having more flexible health services that allow access without a fixed address, GP access cards that can be handed to receptionists to facilitate registration, and support for navigating literacy barriers were said to support access to healthcare.

So I've managed to get public health to provide me with local doctor's surgeries. And we've also got like a little yellow card that you can hold up which says something like, you know, 'I struggle to read or write. You know, I don't have to have a fixed address to get...' some prompts for the doctor's surgery. Remind them I might be an Irish Traveller, but actually, I am entitled to be seen.

Local authority participant, England

Participants felt it important that health practitioners develop a better understanding of Gypsy and Traveller culture, ways of life and communication needs, with greater awareness and empathy seen as supporting engagement, trust and relationship building.

I think nowadays, there needs to be... a bit more knowledge of Gypsies and Travellers. That's what it is... They need to be able to pick up on...how we say things. I mean, I can say I've got a headache, but actually, I really want to put my head through a window because I'm in that much pain. But I will say, I've got pain in the side of my head. I mean, take, for instance, I went to the doctors, and these three years, nearly they said to me, you've got an ear infection, or throat infection. Have you got toothache? No, I haven't got toothache, it's down one side of my head, you know, things like that. And it took me ages to actually, till in the end, we walked in, and just started crying and I sat with the doctor, I said look I can't cope no more. But it got to that point whereas if you had somebody even from our community, that could, even though we speak very good English to translate the fact of what we're meaning...I think they need more training...on who Gypsies and Travellers are, how their terminology is, how they speak about things.

Female, aged 70 to 80 years, bricks and mortar

The need for training of healthcare providers, and particularly of reception staff, was raised as an important route to improve awareness of Gypsy and Traveller culture. Accountability mechanisms to then ensure appropriate communication approaches were being followed by healthcare providers were seen as a potential mechanism to address any discriminatory practices.

We have to always go back to this prejudice and we experience it in everyday life. So the answer is education. You need to inform health workers how they work with community. What you were saying about our cleaning rituals are important to us. You know, laying someone out after they die... a few little things makes it a lot easier for us, [knowing] about our cultural norms [cultural practices].

Community member, Focus Group 2

For more information on cultural practices, please see <u>Gypsies' and Travellers' lived experiences, culture and identities</u>, England and Wales: 2022 bulletin.

Central and local government participants also highlighted the need for more robust and timely data about Gypsy and Traveller communities to understand and plan more effectively to meet their healthcare needs.

Anecdotal stuff that we've got through the [civil society organisation name] already is that there's often a fear of discrimination. So people won't necessarily declare that they're from the Gypsy, Roma, Traveller community just because of fear that they may potentially not receive a similar level of care as if they weren't from that cohort. Which then also makes the challenge harder for us from a data perspective because often then people that have registered with a GP or are engaging in these services won't declare that they're from said community. So then when we're looking from a data for analysis point of view to try and understand some of the health needs, it makes it challenging because there's big gaps in the data and in terms of, we're talking relatively low numbers of people that may have declared...

Local authority participant, England

So yeah, even some really basic things that you would just expect because other groups and ethnicities are on the [Health] Data Dictionary to track health inequalities... You think, oh, it must be easy to add some, but apparently not... So there's just even simple things and a massive hard slog to get any sort of progress on that.

Central government participant, England

8. Gypsies and Travellers in England and Wales, data

Please note, as this is a qualitative study based on data collected from interviews and focus groups, there is no accompanying dataset.

9. Glossary

Bricks and mortar

This term is used commonly by Gypsies and Travellers when talking about homes which are permanent structures, such as houses or flats.

Participants

In this bulletin, "community members" and "participants" refers to people currently living in England and Wales, aged 16 years and over, identifying as Gypsy or Traveller, who took part in this research. Where quotes have been used from local or central government participants, this is explicitly stated. We aim to portray the views of participants and to reflect their words as closely as possible. Some quotes have been edited for language and grammar to improve accessibility, without changing the content or meaning.

Roadside

Living at the roadside means staying temporarily on public land, such as in a car park or on a verge next to a road.

Sites

Gypsy and Traveller sites are authorised places of residence which may be owned and managed by the council or privately.

10. Methodology

More information about the background and rationale, approach to sampling and recruitment, strengths and limitations, design of the material and approach to analysis can be found in our accompanying methodology.

11. Cite this statistical bulletin

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