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The Right to Health of Gypsy, Roma and Traveller Communities in the East of England
A submission to the UN Committee on Economic, Social and Cultural Rights

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1. Background

In the last Concluding Observations, from 2016, the UN Committee on Economic, Social and Cultural Rights (CESCR) urged the UK to "take steps to ensure that… Roma, Gipsies and Travellers have access to all necessary health-care services and [reminded the UK] that health facilities, goods and services should be accessible to everyone without discrimination".[1]

In its 2023 List of Issues, the CESCR asked for information about "the impact and concrete results achieved through the guidance provided by the National Health Service, the Migrant health guide, guidance on health and well-being for asylum-seekers and refugees, strategic planning groups and the Enabling Gypsies, Roma and Travellers plan (2018) in reducing inequality in access to health-care services".[2]

In particular, the CESCR asked the UK Government to respond to, and invited civil society and academics to provide information about, the following issues, among others:

- Information on the Police, Crime, Sentencing and Courts Act 2022, in particular part 4 on "Unauthorized encampments", and its impact on culturally appropriate housing for Roma, Gypsy and Traveller communities.
- Impact and concrete results achieved through the guidance provided by the National Health Service, the Migrant health guide, guidance on health and well-being for asylum-seekers and refugees, strategic planning groups and the Enabling Gypsies, Roma and Travellers plan (2018) in reducing inequality in access to health-care services.
- Steps taken to address the high suicide rate among men, young people and Roma, Gypsy and Traveller communities in all jurisdictions of the State party.
- Information on the measures taken to improve access to education for children from Roma, Gypsy and Traveller communities in all jurisdictions of the State party and to combat the discrimination, bullying and harassment they face in schools.[3]

[1] Committee on Economic, Social and Cultural Rights, 'Concluding Observations: United Kingdom' (2016) UN Doc E/C.12/GBR/CO/6, para 56.
[2] Committee on Economic, Social and Cultural Rights, 'List of issues in relation to the seventh periodic report of United Kingdom of Great Britain and Northern Ireland' (2023) UN Doc E/C.12/GBR/Q/7, para 34.
[3] Committee on Economic, Social and Cultural Rights, 'List of issues in relation to the seventh periodic report of United Kingdom of Great Britain and Northern Ireland' (2023) UN Doc E/C.12/GBR/Q/7, para 32, 34, 35 and 38.

This submission focuses on the right to health. Unfortunately, there is very little substance in the UK Government's response to the CESCR's List of Issues in relation to this right and to social determinants of health inequalities.[4] The concerns persist in relation to stigma, prejudice, discrimination, lack of informational accessibility and lack of cultural acceptability of healthcare for Gypsy, Roma and Traveller communities. This is reflected in the lack of cultural awareness in availability of suitable health professionals, lack of non-English language provision, problems of trust due to lack of cultural competence, lack of understanding of issues around literacy, and ongoing social exclusion, particularly digital exclusion. Therefore, we must considerately request the CESCR to urge the UK to uphold the right to healthcare of Gypsy, Roma and Traveller people without discrimination and prejudice, paying particular attention to cultural acceptability and informational accessibility as essential conditions for making informed decisions.

2. Introduction

This paper identifies a series of concerns about the level of enjoyment of the right to the highest attainable standard of health among Gypsy, Roma and Travelling communities in the East of England. It is based on qualitative evidence in the form of testimonies gathered in 37 peer-to-peer interviews conducted by the four partner organisations – COMPAS, GATE Essex, Oblique Arts, and One Voice 4 Travellers – between June and August 2023.

The evidence was gathered as part of the project *"Building a community of practice to identify strengths, barriers and prioritise solutions to the right of access to healthcare for Travelling Communities"* (NIHR204053), funded by the National Institute for Health and Care Research, between February 2023 and August 2024.

Of the 37 participating in the qualitative research, 32 were content to share their ethnic identity: 19 Gypsies, 10 Roma, 3 Other (including Irish Travellers and Showmen). Most (28) said they had a physical disability, and one-third (12) said they had an emotional/mental disability. 10 declared both physical and emotional/mental disabilities). Most (22) live in bricks and mortar. Others live on Traveller sites, Transit/ emergency stopping, Roadside/ unauthorised encampment, or were homeless (13). Most were in Cambridgeshire and Peterborough **(**17) and Essex (12), Others were in Hertfordshire, Norfolk and Suffolk (6). Two-thirds (21) could not read or write. Even more (25) could not use the internet.

3. The Right to the Highest Attainable Standard of Health

Article 12 ICESCR recognises the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. Under Article 2(2) ICESCR, the right to health must be ensured without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Gypsy, Roma and Traveller people in the UK, along with everybody else, are entitled to the highest attainable standard of physical and mental health without discrimination.

The human right to health is not a right to be healthy. It is the right to the highest attainable level of mental and physical health. Being healthy is the result of various factors, only some of which the state can have influence on. The right to health entails both freedoms and

[4] The United Kingdom's Response to the Committee on Economic, Social and Cultural Rights' List of Issues Report (August 2024), UN Doc E/C.12/GBR/RQ/7.

entitlements from the state. At the heart of the right to health is "the right to control one's health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation".[5] The right revolves around a system of care that operates on a non-discrimination basis. The right to health is an inclusive or holistic right that covers both healthcare and underlying social determinants of health, such as access to safe and potable water, a healthy environment, housing, and nutrition.[6]

The UK is a party to the ICESCR,[7] meaning that it is a legally binding obligation that the UK has voluntary undertaken at the international level.[8] The fact that the UK is bound by the ICESCR does not mean that socio-economic rights like the right to health can be enforced in national courts. The Human Rights Act 1998 only incorporates rights and freedoms set out in the European Convention on Human Rights (ECHR). The ECHR does not directly include the right to health, therefore, neither does the Human Rights Act. This means that Gypsy, Roma and Traveller people in the UK are entitled to the rights within the ICESCR, but they cannot legally challenge and obtain redresses from the state if public authorities fail to satisfy those rights. In its last Concluding Observations on the UK, the CESCR urged the UK "to fully incorporate the Covenant rights into its domestic legal order and ensure that victims of violations of economic, social and cultural rights have full access to effective legal remedies".[9]

4. Stigma, prejudice and discrimination

Gypsy, Roma and Traveller people report multiple examples of prejudice and discrimination in their interaction with health professionals and the NHS system.

Intersectional discrimination against Gypsy, Roma and Traveller people is being increasingly recognised in international human rights case-law. For example, in Yordanova v Bulgaria, a case concerning the removal of Bulgarian nationals of Roma origin from their home, the European Court of Human Rights acknowledged that "the underprivileged status of the applicants group must be a weighty factor in considering approaches to dealing with their unlawful settlement".[10] In ERRC v Bulgaria, a case about racial segregation of Romani women in maternity wards, the European Committee of Social Rights echoed the Committee on the Elimination of Discrimination Against Woman (CEDAW), stating that "when it comes to the vulnerable situation of certain communities, including Roma women, the CEDAW Committee has already highlighted the need for giving special attention to the health needs and rights of women belonging to vulnerable and disadvantaged groups and to intersectional discrimination on the grounds of sex, ethnic origin, and the low economic status of the victim".[11] When it

[5] Committee on Economic, Social and Cultural Rights, 'General Comment 14: The Right to the Highest Attainable Standard of Health' (2000) UN Doc E/C.12/2000/4, para 8.
[6] Ibid, para 11.
[7] OHCHR, 'United Kingdom of Great Britain and Northern Ireland Ratification Status' (United Nations Treaty Bodies | Body Database, 2022) https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Treaty.aspx?Treaty=CESCR&Lang=en
[8] Vienna Convention on the Law of Treaties (adopted 23 May 1969, entered into force 27 January 1980) 1155 UNTS 331 Art 26; UNGA, 'Report of the United Nations High Commissioner for Human Rights' (2016) UN Doc E/2015/59, paras 16-30.
[9] Committee on Economic, Social and Cultural Rights, 'Concluding Observations: United Kingdom' (2016) UN Doc E/C.12/GBR/CO/6, para 6.
[10] Yordanova and Others v. Bulgaria, App No 25446/06 (ECHR, 24 April 2012), para 133.
[11] ECSR 'European Roma Rights Centre (ERRC) v. Bulgaria' Collective Compliant No 151/2017 (22 May 2017), para 29; CEDAW General Comment No. 24: Article 12 of the Convention (1999) Un Doc A/54/28/Rev.1, para 6.

comes to a historically and structurally marginalised and excluded social group, such as Gypsy, Roma and Traveller people, the principles of non-discrimination must mean that public authorities should pay particular attention to their specific circumstances and culture.

Many of the participants in the qualitative evidence gathering sessions with the four partner organisations reported examples of real or perceived stigma, discrimination and prejudice. A few examples are provided here:

> COMPAS 01: "But they still won't talk to you normally, but they will yell at you. Well, I'm not a little child and I'm not a dog that she would yell at me or at him."
> Interviewer: "And have you done anything about it. Didn't you complain through someone?"
> COMPAS 01: "I didn't complain either, because I don't know who to go to, who to talk to about it, and how to talk to them if you don't know English."
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> COMPAS 06: "Even at the reception, some people are terribly unpleasant, they usually remove you from there, they are not at all interested in talking with us or calling somewhere or some doctor, whether he would take us or not at all. Absolutely no. They are not willing to talk to us at all."
> Interviewer: "Why do you think that is?"
> COMPAS 06: "I don't know. Maybe because we are Roma."
>
> COMPAS 06 talking about receptionist: "Some are unpleasant. That's what I'm saying, but I don't know them by name."
> COMPAS 07: "But it's not because we are Roma, they do that to everyone."
> COMPAS 06: "Maybe. Sometimes it's even in that."
> COMPAS 07: "It hasn't happened directly to me yet."
> COMPAS 06: "Well, my nurse once told me that I should lose weight, that I look terrible, and she was much bigger than me."
> COMPAS 07: "But that's not a question about whether they mistreat Roma."
> COMPAS 06: "But yeah, they do sometimes."
>
> Interviewer: "So, you think that language is one barrier? Do you still think that there are other barriers, why are they not interested in your case as they should be?"
> COMPAS 10: "I think there is discrimination."
> COMPAS 8: "Yes, or they keep saying that I've been here for over 16 years and that I can't speak English. I do not know. I used to go to work, but there were mostly Poles and Slovaks there. With whom should I learn?"
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> OV4 often chooses not to disclose he is a Gypsy: "You do try to hide it because otherwise you think, I don't know if they would treat you different, but you think to yourself that they could."
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> OV6 feels she is treated differently by healthcare workers, saying: "When you go in and if you tell them who you are, and I say if you tell them who you are, you tend to be treated a bit differently. I don't say they don't look, the medical care is the same, but the conversations are definitely different… They drop the word in young people like you in your culture. I understand that you've got family want to come and see you, but what we do here is this and that. But in your culture it's very like that."

OV8 feels she is often not heard because she is a Traveller.
Interviewer: "What sort of thing made it harder to get the care?"
OV8: "Travel can be a bit of a struggle sometimes. And I don't feel like I'm heard a lot of the time because they do see Traveller in my online records. So like, they just kind of presume things. A lot of the time, whether they actually do or not, maybe that's a predisposed thing I've got in my head, but it can feel like that."
And later she says: "So, especially when I was younger, I used to not put down that I was from the Gypsy community. I used to just say, I was 'White British' and not give them any other information. Now, I want to embrace that part of me a bit more. So, I have started to put that down, but I am noticing a difference in how I get treated."

OV10 talking about being treated differently: "I mean, if you call over the phone, sometimes it's okay. I have found when you're in the surgery and a person can sort of see what you are, and then their attitude just changes. They can be so helpful and assist them with the person in front of you. And then when it's your turn to speak to them, and their attitude just changes. Like you're lucky you should be there, basically."

OV3 and OV2 talk about stigma putting off GRT community seeking health care:
OV3: "Because they don't want to go to places because, you know, if you fall and try to reach out, if you're, like, if your child falls over, and you're taking them in, you guaranteed they're gonna be looking at you weird. Have you beaten them? Have you done this?"
OV2: "Yeah, by your background and your community, because if they know you're a Traveller, you go like school or anywhere, you're instantly put upon that image of you're gonna hit someone, you've done something wrong. You shouldn't be here, get out, that kind of thing. So, it's very hard to get help. You don't feel like you're wanting that."

Interviewer: "And have you ever experienced problems with the NHS because of racism or discrimination?"
OA2: "Yes and no. My sister dresses more like a Gypsy than I do. I'm very well educated. She's not, so my aunt's very seriously sick. Can the doctors and nurses speak differently than they do? They treat them differently and speak differently."
OA9: "[Suicide rates are] higher for traveling people. It never did happen before, but now do. Because traveling people they're embarrassed, people look down on them and say 'Oh, they're mad. Keep away from them'."

5. Informational accessibility and cultural acceptability of health

The CESCR has developed and regularly applies four interrelated and essential elements of the right to the highest attainable standard of health: Availability, Accessibility, Acceptability, and Quality of the care (AAAQ criteria).[12]

- Availability: There must be enough healthcare facilities, goods, and services. What constitutes a sufficient quantity may vary depending on factors including the economic status of the state, the underlying determinants of health, and the number of trained professionals.

[12] Committee on Economic, Social and Cultural Rights, 'General Comment 14: The Right to the Highest Attainable Standard of Health' (2000) UN Doc E/C.12/2000/4, para 12.

- Accessibility: Facilities, goods, and services must be accessible on a non-discriminatory basis. This includes physical and economic accessibility as well as ensuring the means of access is safe and appropriate for the population. Particular care needs to be given to ensure accessibility for those in situations of social vulnerability, including ethnic minorities, the elderly, adolescents and children, and those with disabilities and chronic or terminal illnesses. The right to health includes informational accessibility, meaning individuals should be able to understand information concerning their health and healthcare. Informational accessibility is intended to ensure patients can understand and participate in their own healthcare decisions and in decisions that affect the underlying determinants of health.
- Acceptability: Health providers must be respectful of the culture of individuals, particularly those from ethnic minorities, such as Gypsy, Roma and Traveller communities. This includes ensuring the facilities and practitioners are sensitive to gender requirements and protect confidentiality.
- Quality: The goods and services must be of a good quality scientifically and medically. This includes appropriate hospital and care equipment, adequate sanitation, and adequate medical provisions, in line with WHO standards.

The testimonies gathered by COMPAS, GATE Essex, Oblique Arts, and One Voice 4 Travellers raise serious concerns about inadequate access to healthcare by Gypsy, Roma and Traveller people in the East of England, particularly in relation to the essential criteria of informational accessibility and cultural acceptability of health. Some examples are provided here:

> COMPAS 01 believed the appointment was at 11 and then was told when he arrived that the appointment was not in the system. He found this very frustrating: "How is it possible that we were here in the morning and you didn't send us a text, right, nothing. And if we knew we didn't have an appointment, we wouldn't go there. We were there in the morning. We are 'let's make an appointment at 11 o'clock so we are here at 11 o'clock'. That's not my problem, that's your problem. Well, they also sent him a paper, a reminder that one more time, to throw him out of the register for the fact that he shouted, cursed, shouted."
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> No interpreter is offered when they go to the doctor:
> Interviewer: "So don't they automatically assign an interpreter if you don't speak English? Like don't they do that anymore?"
> COMPAS 02: "They don0't, it was normal before. Well, yes, it would certainly be good, there are not many Czech speaking there. One lady works in the pharmacy, Slovakia."
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> COMPAS 08: "Well, I'm trying to speak English, because otherwise, even if they are Polish, they don't want to speak Polish. There is a Lithuanian woman there, but I can't understand English when she speaks. I tell her that I want to make an appointment and she tells me to go to the computer and make one online."
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> COMPAS 01 finds it impossible to make an appointment using the app: "Same. I can't write English, I can't read. Well, I don't know how to make an appointment through the application."

Interviewer: “And how did you make an appointment with the doctor? Over the phone, over the computer?”
COMPAS 03: “Online, via computer. Via PC. Because I’m not that good at it over the phone and sometimes it shows me that a different password. Then I had to call there, say that I can’t do it, that it’s not possible. I just don’t see why. Well, in the end she told me how to do it all, so I got there.”

COMPAS 08: “At the reception, since when they put the online system there. They said that it was not their job to help us. When my sicknote finishes, I’m going to the reception to ask them to extend it for me. She says I should do it online because it’s not her job.”

OV4 notes lots of problems with communication some of which are because he can’t read:
OV4: “The first thing they do is hand you a leaflet. They might as well hand me a bit of toilet paper… You know, it’s about as useful. And when they fill in the form, you say even though I can’t read or write properly, they sort of flip over the questions, or they say ‘well we’ll read them to you’. And you just say yes or no. Well, the time they’ve read them, you don’t understand half of them. And also, like, I was just saying lightly, like, when you’re talking to your doctor, get a letter, and you take it to somebody to get it read, they come up with all these abbreviations, whatever. And I ain’t got a clue what they are, you know.”
Interviewer: “Do you feel that you could ask or do you feel?”
OV4: “Well, you know, you don’t want to make yourself look stupid. You’re a grown man, over 60-odd year old, asking him what does this mean?”

OV9 is not literate and finds it impossible to navigate the system when he needs healthcare.
Interviewer: “And what about actually making the appointments or talking to the reception? How do you find out?”
OV9: “I can’t really do that. I have to get somebody else to do it for me. I’m a little bit mentally behind myself. I don’t know what it is, and I get all tired and tangled up about trying to make appointments and things for myself and I forget the dates, I forget the times, so I need help continuously.”

OV4 reported not understanding his consultant:
Interviewer: “What do you feel like about the consultants in hospital?”
OA4: “And once again, they’re a total riddle, some of them. They talk in total riddles, some of them. They don’t explain nothing to you. Now ask them a question, ‘here you go, here's a leaflet’. Or what we’re going to do is we’re going to do this and do that and do this.”

OV5 also complained about misunderstood communication with healthcare workers as he thought he was going to get treatment but when he got to the hospital it was just a check-up: “And she come and she said, right, just take the bandage off. When she looked at it and she said, yeah, that's all okay. Said, okay, so what do I do now? So, we’d go home, come back, see us again in four weeks. I said, what’d they come through here today for? Well, you need to check it. Well, nobody told me. He was just checking it. I could tell you that it was all right over the phone. They didn’t have a clue. They didn’t have a clue what they were doing.”

Interviewer: “And we’ve talked about, you had issues with online forms and trying to…”
OA6: “Yeah, because I can’t read and write, so...”
Interviewer: “Explain to me how that works and the difficulty you’ve had with that.”
OA6: “A lot of problems, cos I can’t - the phone, the kids have got to do it. Because I can’t you know what I mean? If I want something on the phone, then just ask Google. Yeah, that’s the only thing we can do because that’s useless.”
Interviewer: “Yeah. Have you found through healthcare, you’ve had a lot of problems?”
OA6: “You’ve got to do stuff online. That’s why we come down here, you need to do it for us because we ain’t got access to all this at home. So, find that really hard. Every Wednesday we come down here and they do it… They help on the laptops and things. All right, but if he asked me to do anything, a lot of the time I can’t do it because this is the reason, right? It’s a bit hard for me when it comes to stuff like, documents and stuff.”

OA9: “Like my brother died a couple months ago and 10 years he suffered with cancer and never got his chemo, never got nothing because he couldn’t read and write. And when he’d ring up and try to get an appointment, he was told when he’d go to a doctor, he was told you have to ring at eight o’clock in the morning and a doctor would call you back or you had to go on the computer. He couldn’t read and write. He didn’t understand, he used to have a Nokia phone. He couldn’t use another phone, he didn’t do internet. And this is another thing, travellers, a lot of them don’t do internet because they’ve never learnt it. They’ve never had computers. A lot of them have never had lectures to work on computer.”

GE1: “That's really difficult because we’ve had to do things online but my NHS app is not accepting the email address and it’s not accepting the address. It doesn’t accept the address, it keeps coming up that the address is invalid, the postcode’s invalid so it won’t, it won’t actually add it… They were supposed to set it so we can do the prescription and things online. But we couldn’t do it.”

In addition, recently published research by Dunn, Tuner-Moss, Carpenter, Speed, Dixon and Blumenfeld shows that the wide range of socioeconomic and cultural factors present in Gypsy, Roma and Traveller communities, combined with low literacy, act synergistically to worsen the physical and mental health of Gypsy, Roma and Traveller groups in different ways than that seen in members of the general population with similar low literacy levels. National intervention is required to improve the literacy of Gypsy, Roma and Traveller children and adults. There is a clear need to develop policies and processes that facilitate a better understanding of literacy levels and how they interact with other social determinants of Gypsy, Roma and Traveller health among healthcare professionals.[13]

In April and May 2024, researchers in the project compiled a number of suggestions for action to ensure the cultural adequacy of public healthcare and improve communication between health professionals and Gypsy, Roma and Travellers. This includes: the creation of community intermediaries, greater direct engagement with community leaders and representatives, using community translators, communicating via WhatsApp, asking how help

[13] Dunn M, Turner-Moss EJC, Carpenter B, *et al*, The effects of literacy on health in Gypsies, Roma and Travellers (GRT): a systematic review and narrative synthesis, *BMJ Global Health* 2024;9:e017277.

can be provided if not in writing, considering voice and/or video messages instead of texts, greater use of easy-read formats and visuals, and providing options for flexible appointment scheduling when possible. The full list of recommendations is available upon request.

6. Conclusions and recommendations

In August 2024, the UN Committee on the Elimination of Racial Discrimination raised concerns "about the adverse impact of structural inequalities in social determinants of health and in access to affordable and quality health care of persons belonging to ethnic minorities" in the UK, including Gypsies, Roma and Travellers.[14]

The testimonies and qualitative evidence compiled in this document are the unreserved confirmation that the concerns persist in relation to stigma, prejudice, discrimination, lack of informational accessibility and lack of cultural acceptability of healthcare for Gypsy, Roma and Traveller communities. This is reflected in the lack of cultural awareness in availability of suitable health professionals, lack of non-English language provision, problems of trust due to lack of cultural competence, lack of understanding of issues around literacy, and ongoing social exclusion, particularly digital exclusion.

Therefore, we respectfully ask the CESCR to reiterate in the 7th review its past recommendations and to urge the UK to uphold the right to healthcare of Gypsy, Roma and Traveller people without discrimination and prejudice, paying particular attention to cultural acceptability and informational accessibility as essential conditions for making informed decisions.

We also request the CESCR to reiterate its recommendation to incorporate all the rights contained in ICESCR, including the right to health, in the UK's domestic legal framework, including the right to remedy for violations of these rights.[15]

[14] Committee on the Elimination of Racial Discrimination, 'Concluding Observations: United Kingdom' (2024) UN Doc CERD/C/GBR/CO/24-26, para 43.
[15] Committee on Economic, Social and Cultural Rights, 'Concluding Observations: United Kingdom' (2016) UN Doc E/C.12/GBR/CO/6, para 6.