00:00:18 to 00:05:05

Welcome

Dr Kostis Roussos, Director of Research, School of Health & Social Care, University of Essex

Hi everyone. My name is Kostis Roussos, and I'm the Director of Research in the School of Health and Social Care and on behalf of the University of Essex and the school of health and social care. I'm very happy to welcome you to this event on health inequalities and barriers to accessing healthcare for Gypsies, Roma and Travellers.

Inequality and exclusion for one person or one group due to their culture, race, or colour of their skin is inequality and exclusion for all. This is an important topic that demands attention. It demands collaborations and of course, action. And we're grateful to have such a dedicated group here today and also online.

The speakers and agenda today touch upon some of the most critical issues in tackling access to healthcare and healthcare for Gypsies, Roma and Travellers in particular. It is very important to understand how interconnected forms of inequality and exclusion shape barriers to healthcare access, Gypsy, Roma and Traveller communities often face entrenched inequalities in accessing healthcare due to systematic, to systemic barriers, such as discrimination, inequalities, racism, lack of cultural competence and cultural humility in services, and, of course, broader social exclusion. These challenges not only affect the individuals and families within these communities, but also highlight gaps in our healthcare systems and the broader social welfare system that affect us all. Access to healthcare is not just a policy issue. It's not just a healthcare professionals’ issue. It is a fundamental human right recognized by international frameworks like the Universal Declaration of Human Rights and the World Health Organization. Yet for Gypsy, Roma and Traveller communities, this right remains largely unrealized. Discrimination, lack of cultural understanding and systemic bias deprive many of these communities of equitable access to the care they need and the care that they deserve, and addressing these inequalities is not just about improving public health, but it is a matter of social justice. Realizing a human right and justice framework, then to healthcare often begins at the grassroots level at the community level with trusted practitioners and effective collaboration with communities for everyone, not only for Gypsy, Roma and Traveler Communities trust is a critical factor in accessing healthcare. Practitioners who understand and respect cultural difference and community-led initiatives that aim to bridge gaps in understanding have been shown to make a significant difference, and these partnerships help to dismantle those systemic barriers and to create culturally competent care, but also restore trust where it has been lost. And the research that we'll be discussing today brings all these elements together and aims in a way to deepen our understanding of these barriers, but also offers ways that we can work together to identify practical solutions, so to effectuate chains. So this event, this workshop is an opportunity to learn more from one another. To share research insights, but also best practice and experiences with the aim to contribute to more equitable healthcare systems. Your insights and experiences are invaluable, and I encourage everyone here and online to participate fully.

Thank you also, again, for your commitment to this important research to this important practice. Let's make the most of today's discussions to drive meaningful change. And now I will ask Professor Ewen Speed and Sally Barrows to introduce the day and their research. Thank you very much. Thank you.

00:07:33 to 00:22:03 PLEASE CUT 00:16:32 TO 15:52
Overview of the research
Sally Burrows, University of Essex

Hello, everyone. It's good to see you today. I am going to give you an overview of this research project and how it started and what we did, and then we'll get into more depth through the day.

Ewen, Gill and I, and others in the room, are part of the National Institute for Health Research Applied Research collaboration in the East of England, and we sit within the inclusive involvement in research theme, meaning that we're particularly focused on listening to people finding ways to research, people who are often less represented for all sorts of reasons.

I started work engaging with people in Thurrock a few years back and finding out what matters to people, what kind of research that they might be interested in doing with us, and in talking to people and looking at the local area, learned that there is an enormous Travellers site in Thurrock. The South Ockendon site on Buckles Lane is actually one of the largest in Europe, though we don't hear about it very much. Unsurprisingly, health organizations, charities, and so on, were concerned for the health of people there as well as others from Gypsy, Roma and Travelling communities living in the surrounding areas.

I think most of you here today know how stark the inequalities are in terms of health outcomes and employment housing education, life chances for people from these backgrounds.

I should say, during the course of today, we're not going to talk much about the differences between ethnic groups. We started off talking about “Travelling Communities”, and wanted to include Showmen (there are many living on the site in South Ockendon). As we formed relationships with Gypsy, Roma and Traveller community organizations in the local area, there was an emphasis on how many people are actually in settled accommodation in bricks and mortar. And so we moved away from talking about “Travelling Communities” because we felt that that was adding to a misunderstanding. But there are many communities and ethnic differences. So, as we say, GRT or Gypsies, Roma and Travellers today, please excuse us for that. But this isn't a day where we'll be talking about all those differences. That's for another day.

So yeah, we started off engaging with local community groups and others interested in this area, many different people, to think about what kind of research would be helpful, and it was quite noticeable. That Gypsies, Roma and Travellers clearly wanted more action than research. There was a view that there's been research, you know, in around barriers to access before, and the primary concern, of course, for health practitioners and community members is the crisis of health. You know people are living very short lives for not enough good reason, and there are some serious health problems that people aren't getting help with, so that was understandably their focus.
They said, this has all been done before, and now we want action. We know the issues. But they didn't know the solutions necessarily.

And of course if you're talking about Gypsies, Roma and Travellers, they want to be involved in how things change. Of course they do. And that's right. How can it be good research or policy or practice without those discussions. So we wanted to work together, to look at solutions, and to make the direction of the research quite practical.

This is the project team. I'm not going to read out everyone's names. Most people are here today, and we'll speak to them later.

So the we did development work, research development work. We spoke to Gypsies, Roma and Travellers in the East of England, and checked whether access to healthcare was an issue for them. I think it was 82 people or something in that development stage who shared their thoughts and experiences, feeding in to the project that we applied for and got funding for from the National Institute for Health Research Research for Patient Benefit fund.

So what did we do. We had peer to peer interviews. We thought very carefully about how best to collect information from Gypsies, Roma and Travellers. We wanted to hear their voices, their concerns first, and Beverly and Peter and Shirley and Sherrie from local community organizations supporting families in need and said, “Well, aren't we best placed to do this to have these conversations? We're not going away. We're staying here. Researchers dip in and out. We will understand better. We will be able to communicate with people in the appropriate language.” And of course, these are good points. So they led the peer to peer interviews.

We then had focus groups with health practitioners, local, regional and some national people came along to those focus groups. And then in the final stage, we brought together some of the most experienced and the most passionate who were able to commit to some quite lengthy discussions, building on the knowledge that we'd gained from the first two stages.

Here’s a photo of some of us at a community of practice meeting Rock Road Library (highly recommended venue). And all these people as well: highly recommended!

So involving people in research, in policy, in practice. Well, I firmly believe that's the key to improving outcomes.

And this is what we're looking to achieve. Understanding the barriers to access and finding solutions. That work creating action plans is very much participatory action research that improve access. There's been a lot of talk, as I say about these things about the barriers. But what do we actually do? And how can we do that together? Not just the academics and the policymakers, but really, inclusively. What we ultimately want is the improved health outcomes, and sustained relationships that keep those outcomes getting better.

Who did we speak to? This is very much small scale qualitative research. But 37 Gypsies, Roma and Travellers took part in the peer-to-peer conversations, 35 health professionals in the focus groups, and 21 in the community of practice. So overall, 88 research participants. I'm quite happy with the spread of community members, health practitioners and policymakers that we achieved. I'm also quite happy that all of those different people were drawn from across the east of England, from each integrated care system. In the National Focus groups, I should also say we had input from Senior people from NHS England Inequalities, from the Royal College of General Practitioners, Royal College of Emergency Services, Queen's Nursing Institute, the UK Health Security Agency, and NICE (the National Institute of Clinical Excellence). So I'm happy to say that I think that the solutions that we've come up with do align quite well with the Core 20 plus 5 program.

These are the broad issues identified, we're going to talk about more about this in detail later, but, to give you the overview, communications and these assumptions, these assumptions that everybody speaks English, that everybody understands it, that everybody's digital included these days, or that they can be made to be. Assumptions that everyone reads and writes well, understands health explanations. We'll be talking a lot more about stigma and discrimination. I was amazed how many people work within the health service who have not disclosed to their colleagues their ethnicity. I can guarantee that everybody in this room has worked with Gypsies, Roma and Travellers. There are more than the numbers will count or do count, and perhaps that's partly due to the NHS dictionary’s lack of inclusion of the ethnic groups. But again, I'm sure someone will talk about that later. And there’s this real lack of understanding from both sides, from all sides. You know the community members don't understand the health service system. I'm not sure many of us do, but you know, but there's another level to that of understanding. And certainly there's a lack of cultural understanding from health practitioners. Not all: of course, there are some wonderful practitioners who work very closely with their communities and know them very well.

One thing I will say actually as well is that the health practitioners that we met during those focus groups, and throughout this project, because there've been more people involved than were actual participants, as I'm sure you know, in the audience. But the health practitioners really valued talking with each other and having an opportunity to say, “This is how it goes for me. These are my experiences. What would you do? How do you do that?” And that sharing is something we very much want to encourage.

Solutions. We're going to talk more about trusted practitioners, and what can be done to make that less of a postcode lottery and more common, and the role that perhaps community groups, and certainly Gypsy and Traveller and Roma community members could play in bridging this gap of understanding and communication and overcoming the daily onslaught of stigma and discrimination, actual and perceived, and help build some trust.

At the final stage we pulled together some we all believe, quite realistic action plans that can be achieved in the short term, because if we want to build that trust, we want to start things moving, it's very important that something visible happens that people notice, otherwise this will be seen by the communities as another research project that has not made as much difference as it could have done, and people would be left feeling uncared for and forgotten again.

These are the action plans. The broad topics. They are being developed and progressed as we speak: we will be listening to you all today and incorporating your ideas, and hopefully, more of you will link in. There is a making connections form which is a Google form. If you fill your details in there and say, what your interests are, I will circulate that on Tuesday next week, and you can all link in with each other, because I think that is what many of you would appreciate. And of course, feel free to contact Ewen and I as well. Thank you.

00:26:13 TO 00:32:21
Petr Torak
CEO of Compas charity, Peterborough

Morning. So I'm Petr Torak. I'm CEO of a compass charity based in Peterborough, but we cover also all the parts of the UK. We predominantly work with advice, provision, mentoring and also managing Roma archives. Majority of our clients are Roma communities and members of Roma communities from Czech Republic, Slovakia, and Romania, but we also help anyone else that comes through the door.

Our part in this project was to do research within the Roma communities from those countries that are mentioned, the migrant Roma communities and what was very apparent from all the conversations and the interviews was the issues with interpreting obviously majority of the Roma people that come into the UK, or came here 5, 10, 20, or so years. They have got different levels of English, and especially the older generation. The generation that came here when they were 50 plus. They obviously struggled to learn fluent English, and to not rely on their children or on their grandchildren or other members of the community, and this makes them much more vulnerable. So that's the ability to speak English.

The second thing that also was playing a very vital role was the fact that a number of people were also finding it very difficult to understand even their native language. Quite often the surgeries would use interpreters from Czech Republic or Slovakia Romania interpreters that are professional Czech Slovakian speakers, quite often even academic speakers, and the Roma members would find it difficult to understand, because, you know, we would have to go a bit deeper to look at the situation in contemporary Europe, where Roma still, until today, in many European countries are placed into special education. So for this reason, the quality of the education that Roma get is not equal, it's not the same. It's not adequate for them, then, to be able to understand academic or very professional language, that those interpreters would be using. So the language, interpretation, understanding, overall, and communicating with GP surgeries, whether it was with the GP, nurse or the receptionist, was an issue, and the biggest issue in this case.

We've also observed quite interesting comments that quite often, even if the surgeries went a step further, and they employed multilingual staff to the reception, very often in most of the cases that actually that we've noticed, the receptionist would come across to would be, let's say, Czech, Slovakian or Romanian receptionist, but most of the time actually, they were non Roma and, you know, due to the ongoing prejudices, discrimination, and stereotypical view of Roma people in those countries, such as the Czech Republic, Slovakia, Romania, those people quite often at a reception, would display their prejudices even here in the UK. So very often, we were told by those participants, those that were interviewed, that as soon as they would report to the reception, the receptionist would judge them by the way they look, speak, or where they come from. And they felt quite often uncomfortable talking to the receptionist, and quite often they would not even get past the receptionist to see a nurse or a GP. So if they manage to get an appointment if there is an interpreter they struggle to understand. If they are given a leaflet, it's any language that they struggle to understand as well and quite often. The people you know that we spoke to said to us that what would help, you know, to kind of change this status quo would be to have somebody from within the community,

community ambassadors, community interpreters, whatever you would call it, but somebody from within the Roma community that would be representing, you know, the NHS. But at the same time the Roma community was able to communicate with the members of Roma community in their native language, or in the way that they would understand, and also that would not have potentially stereotypical views towards the Roma people. So these were the main discussions we were also talking about booking appointment. How difficult it is for somebody anyway? So somebody that can't speak properly English, and for a patient to actually make a phone call in the morning, 8 o'clock in the morning and you know, to call or to book online on their mobile phone or on a computer, an appointment is practically impossible. And then, obviously, there are associated issues where you are going to use your children or your family members to translate, but that means quite often that parents will take their children out of the school for them to interpret at the GP surgery, and then parents will get into trouble and get a fine from the school because of poor attendance. So all these issues were associated with the lack of understanding and communication barriers.

So yeah, I will stop here, and I'm more than happy to answer any questions now or later.

Question: So do you find that…? I worked with one remote family when I did my old role, and the understanding of how bodily, how bodies work is perhaps quite basic, or they might have very specific language that relates to specific body parts that wouldn't necessarily be obvious to somebody who wasn't from the community?

Petr Torak: Yes, obviously, definitely, you know, like, for especially the Roma communities that are still living in a very segregated marginalized communities, let's say, in Eastern Slovakia, where you have got villages only for Roma people, it is 100% of Roma people living in substandard accommodation. You cannot even call it accommodation. It's a wooden kind of like wooden shed, with no electricity, no gas, no running water you know. Children have to, you know, sleep in like this shed that has got maybe 4 by 4 meters with parents, and maybe another 6 siblings quite often bitten by rats, and you know, so on so coming from this sort of kind of environment. Yes, you develop your own language, your own understanding, but also your own belief. What is good for you what is you know what is correct, and also you are quite often forced to, you know, change your habits, you know. So you eat whatever you know like, especially in poverty you know, you eat things that are cheapest, you know. And so all these things obviously will have a big effect the same taboo. Taboos that are within some of the traditional Roma families, you know, and things that people are not comfortable talking about, especially when it comes to from the youth if a mother takes her child to a GP to translate. But then the doctor starts, you know, asking about maybe women's health, and you know, so this sort of taboos and situations where people might not be comfortable to talk and express their problems freely, because of you know their own perceptions. But and also another thing that was quite often mentioned by our patients was the perceived barriers as well. You know, their experiences from their home countries, because you know of the discrimination and marginalization their view of doctors' police officers, teachers is quite often, you know, like very, you treat them with very caution, because you know, quite often they would be abused by those authorities. Women from Roma, women in Czech Republic and Slovakia were sterilized until 2004. My mum was one of those women and was sterilized. You know it was a state policy during the Communist regime to sterilize Roma women to reduce the number of Roma children. So you know, coming from this sort of background, your kind of trust towards those authorities is very limited, and that's something that also play a big role.

Thank you, Petr. Thank you. Are there are there any more questions online, or in the room?

Question: We have more of a statement here, and somebody said that my understanding was that Roma are often very excluded from mainstream education in some parts of Europe they are often pushed into special schools when they don't have learning difficulties.

Petr Torak: Yeah, that's true. As I mentioned, yeah, the substandard education for Roma children is still happening today, Roma are placed either within mainstream schools into segregated classrooms, or there are completely segregated schools for Roma children because they are deemed to be disabled or unable to perform as non Roma children, and so they are placed into schools for disabled, whether it's mentally or physically schools children into those schools. Obviously, there's, you know, more. And there's loads, you know, we could talk about I'll put here my email address in the into the chat. If anybody wants. Obviously, I can see that you want to have a conversation if you want to contact us, obviously free to contact me directly or through. Ewen and Sally.

Question: I'm just wondering how best to discover where our Roma folks live, and how we could best connect with them.

Petr Torak: through my previous job. I was a police officer in Peterborough. The best ways to engage and to find actually, the Roma community is through a number of different streams. One would be schools. Quite often they would work with the Roma communities. They would be aware of the families. Second would be local community centres. If there are like community groups such as a Compas charity in Peterborough. So those groups, those community groups would know. And then 3rd would be a church to see if there's either a Roma led church quite often Roma would be in the Christian Protestant or you know all the churches, or if not, if there's not a Roma at church, then see if the local church would also know, because quite often Roma would go to some sort of church.

And how to best, how to how to connect with the Roma community. I always advise whether it's the police, prison service, social services, schools, and so on. I always say that the best practice and the best way you know to engage with Roma community is to employ somebody from within this community, because this this always works. And I think that's the right thing to do as well.

00:40:21 to 00:54:06
Beverley Carpenter
Oblique Arts Traveller Advocacy Project

Hello everyone. Nice to see you all today and everyone online. My name is Beverly Carpenter. I'm from Oblique Arts. We are a small charity based in Cambridge, and we work across Cambridge. Here our management is partly GRT, and we have worked for 15 years with GRT communities. And we run creative literacy workshop projects and advocacy project weekly and also exhibitions and cultural events, including art curation for the World Roma Congress, and a number of other activities. Oblique Arts has been one of the organizations, the partners gathering evidence for this project with interviews with community members. And I've been part of the community practice, and we have some as you know, we have some ambitious goals with this project which we'd really like to see realized. And I'm going to discuss cultural competency and discrimination a little bit today with you.

I feel quite strongly about the need to improve the variable delivery of the health services across our region, which yeah, can be, quite challenging, I think, for community members to negotiate. Yeah, be difficult, I think, then, to negotiate this really variable quality of delivery. So I'm going to start with a few examples from our GRT interviewees about access and services. We asked, what does good health look like to you? And some of the answers were:

"Healthy means seeing your grandchildren nowadays not dying before you are 50."

"Healthy means, living without fear, pain, or suicidal thoughts."

"Healthy is feeling okay, safe in your own home."

Women are scared of having their children taken away and stay in abusive relationships, often risking their lives rather than getting help.

We asked. What is it like trying to get help, access to health care? And the kind of responses that we got were:

"You feel as if you are judged for who you are."

"don't feel comfortable going to the surgery."

"It's not confidential. You have to tell the receptionist all of the personal details of your illness."

"If a doctor sends me a letter, and I take it to somebody to get it read. They come up with all the abbreviations, and I haven't got a clue what they are."

"When you're homeless, it's almost impossible to get help from a doctor."

Yeah, this is fairly variable again, depending on which area and which doctor and which surgery.

We delved a little bit deeper by asking more questions.
Do you feel that you were treated fairly, and interviewees told us:
"Doctors don't believe you. With my seizures 2 or 3 times per day I was begging them for help when I was pregnant, especially they think you're trying to get benefits or lying to them."

"I've not been believed. A nurse didn't believe me when I said I wanted to change my birth control. I had so much pain with a coil. I'm often treated as if I'm stupid."

"I can't get the drugs that I need in some places during episodes of post-traumatic stress it varies with each surgery." This is a person who's traveling.

"I was not treated well and very differently to other women."

"It made me feel awful. My son almost died. My son was lactose intolerant. I knew it, but they wouldn't believe me."

And then, as a result of this, this research on these things, we also asked interviewees what they thought that health professionals needed to know, and what we heard was:

"There is a lot of mental health problems. I would like to be treated better and believed."

"It would be good to be treated the same as the other people who go in."

"It's the phone lines, and the way you can't get to see anyone. I'd like to be listened to."

We also heard that having to having to do your own patient care online has been really, really problematic.

"We have to come down to GRT organizations if we can for them to put in forms for us. We haven't got access to any of this at home. So it's really really difficult."

As a result of this feedback, as you know, we've done, we've done a lot of work as part of our team, and we've come up with action plans around cultural competency, and also, you know, as part of this addressing racism, which is inherent within the health service and also wider society. In recent studies, a third of respondents experienced experience, discrimination when accessing healthcare and they also reported that they regularly hid their ethnicity, as we know, in order to access health services and to receive equal treatment. So people said:
"I'm registered as white British. It's just easier. Why, take the risk?"
"My family would never say we're Gypsies in case they refused, refused to give us healthcare."

The Traveler movement has reported widely on racism. In a 2020 survey, they found that 98% of Gypsy, Roma and Traveller respondents said they experience hate, speech or crime. Very often 47 reported being racially assaulted, and 37 have been physically attacked. According to a national survey, 62% of Gypsies and Travellers have experienced racial abuse which is higher than any other minority ethnic group. So we see that human rights legislation is in place, but not effective. That that requires health providers to be respectful of culture, of the culture of individuals, minorities, and people's communities, with the intention to improve the health status of those concerned. However, we still see that the UK Government recognizes that GRT are among the most disadvantaged people in the country and have poor outcomes in key areas, health and education.

We've heard that life expectancy of Irish Travellers is 10 to 12 years less than general population and GRT infants have higher rates of preterm, birth, growth, restriction, mortality. And GRT are significantly more likely to have long term illnesses and disability which limits their ability to function and work at all.

We've heard about receptionists at GP surgeries, and this this the first contact for many really. There was a mystery shopper methodology interview with 100 GP receptionists in the UK. And they found that most GP surgeries were unwilling to register a patient without proof of identity and proof of fixed address, although this is not a legal requirement.

Furthermore, the healthcare environments themselves present barriers to these patients with illegible signage, inappropriate information, and inappropriate communication formats. So healthcare encounters often leave GRT patients feeling lost and this really restricts their ability to advocate for themselves. The idea of feeling unwelcome and having inaccessible information creates a huge anxiety. Some patients can be indirectly excluded from receiving services when their needs are not understood by the surgeries and when patients have low levels of literacy an absence of recognition of their difficulty is itself disempowering. So this leads to yeah, just discrimination around participants who when they go into a place, the first thing that they find really is a leaflet or something that's excluding. And to begin with so we talked a lot in this project about trying to change that about maybe being a bit, maybe changing it through training and other things with health professionals, but also something visible, so that GRT members can go into these places and recognize that there is a certain standard and a non-variable kind of way that they're going to be treated and as a result we've come up with these action plans. And the action plans produced in this research, I think, are really achievable. So yeah, we have a really good chance, I think, of putting this in place, and we have the partners, and suddenly everybody in the right place to go ahead with this and turn this one around.

Cultural competency Action 5, I think, on the poster over there in the far corner is around being organized around 3 key ideas. One is around training for health professionals. One is around advice and guidance, and the other areas around building relationships. So in terms of training, there's a few points that we can try to put in place to review the mandatory equality, diversity and inclusion, training and ensure that there is specific attention to Gypsies, Roma and Travellers and the positive impact of inclusive practice, and we aim to review current training in on offer and make recommendations for improvements. And we aim to collate and share a range of in-depth training opportunities online and in person. Also, we will try to identify GP surgeries and accident emergency departments with higher local populations of GRT and recommend additional training for receptionists and practitioners in those practices with greater patient numbers. So we know it's really variable. And we know in some areas the level of understanding is higher and we should be able to see that practice shared. To co-produce any new training materials with GRT community members and healthcare practitioners to ensure appropriateness. We think that these actions are going to make a difference, and I'm sure we can put those in place.

And the second area that that this action plan covers is advice and guidance. So we will collate a contact list of local charities and community advocates to develop relationships and give advice and guidance and pass advocate contact lists to GP practices and social prescribers. We'll encourage others to use the advocate list, and we will make sure that list is updated regularly by appointing a responsible person to do this.

And the third area is building relationships. So it's really important that GRT communities and health providers come together within an environment that's really conducive to developing the future of this as a long term plan. So we want to set up regional GRT networks where health professionals can meet with community members and we will enable charities to reach out to health organizations, to arrange meetings with staff, to develop links and understanding because things do change. You know the needs do change as time goes on.

And then there are some sort of expected longer term outcomes which seem also perfectly achievable, really. More trusting relationships between Gypsies, Roma, Travellers and health professionals to enable higher quality interactions between GRT and for health professionals. To have more practitioners who are comfortable to visit patients in their own homes often, especially on sites. This, really, you know, doesn't happen much. And we found cases where health professionals won't go out without police present with them. That then creates a whole new level of problems.

And to see longer and healthier lives is the overall aim, reduction of health inequalities across the region.

So yeah, I'm really happy that this project has come together, and that these things seem achievable, and we've got these action plans.

Thank you.

01:42:00 to 01:54:54
Dr Koldo Casla, Senior Lecturer in International Human Rights
University of Essex

So what we did with this research was to look at the evidence that was gathered by the partner groups: by Compas, by GATE Essex, by Oblique Arts, and One Voice for Travellers, to look at the evidence that they compiled in qualitative research, and assess to what extent the evidence shows that their concerns in relation to the rights to health. The right to health is recognized in the International Covenant on Economic, Social and Cultural Rights, and there are certain standards that apply to it. One of them which applies to all human rights really is the principle of non-discrimination, including structural inequalities and intersectional forms of inequality. The idea is that the moment that we are entitled to certain rights, health, or housing, or prohibition of torture. Whatever it is, the protection of the rights needs to ensure that there is no discrimination, meaning that it is not okay for a country to protect these rights but only for certain types of people and other people who have certain protective characteristics are being exclude. That obviously will not be okay and will not be compliant with the treaty.

So in relation to Gypsies, Roma and Travellers, it's important to see whether there are particular reasons to suspect that the level of protection of the right to health for them is lower or of poorer quality than for the rest of the population or the average of the population. Another key principle of the right to health, and applies also to other socioeconomic rights, like housing, like social security, like education, and so on, is the principle of progressive realization, and the other side of the coin is non-retrogression. These principles, progressive realization and non-retrogression mean that States are supposed to progressively advance towards better protection of the rights, meaning that in 1966, when the treaty was adopted, there was assessed a certain level of enjoyment of the rights, and the idea was that in 1976 the right was going to be more widely enjoyed and better protected, and in 1986 even better in 96. And to this point we were supposed to be in a society where not only health, but also housing and health and social security were going to be enjoyed to a much greater extent. Now we all know that that hasn't been the truth, that in relation to many of these rights is not only that there hasn't been progress, but actually there has been a regression, a retrogression, in the language of international law, meaning that there have been certain deliberate measures that have resulted in a worsening enjoyment, worsening condition.

Now in the research. So what we did was we looked at the testimonies that the 4 groups had gathered in the East of England, and then we assessed them in light of the document I mentioned earlier, the General Comment Number 14. General Comment Number 14 is an authoritative document that was put together by the UN Committee on Economic, Social, and Cultural Rights in the year 2000.

And this document is the reference that we all use to make sense of what the right to health entails. So we observed that there were in particular two main broad clusters of topics of, or areas of concern in relation to access to healthcare by Gypsies, Roma and Travellers in the East of England. The first one was the issue of stigma and prejudice which speaks to the issue of non-discrimination. The fact that many Gypsy, Roma and Traveller people feel that they're going to be misinterpreted, misunderstood, not treated sufficiently well, not going to be reasonable adjustments to attend to their specific needs when accessing healthcare. And the other cluster of issues is the issue of information, accessibility, and cultural adequacy of the information on the treatment. The General Comment Number 14 has certain requirements of adequacy, of health care. So the certain conditions that need to be met for researchers and for analysts to conclude that the level of health case is of good quality, is of sufficient quality in a certain country, and these are availability of the services, accessibility of the services, acceptability of the services, including cultural acceptability and overall quality of the services. And I think the testimonies gathered by the four organizations, the partners in the project, show that there are significant concerns in particular, in relation to information, accessibility, and cultural adequacy.

Now, these two issues, it's interesting to highlight these two issues, because these are the same issues that the UN Committee on Economic, social and cultural rights. In the last report on the UK which is from the year to 2016. In that report that committee raised concerns about the level of compliance of the UK in relation to the right to health precisely because they had concerns about these 2 issues, about stigma, prejudice, and about lack of access to information and cultural adequacy. So now we are in the year 2024, nearly, in fact, more than 8 years after that report that the UN produced in 2016, and the same concern seems to persist, based on the qualitative evidence that the four groups put together in the East of England. So the testimonies show that there are multiple examples of social exclusion, of digital exclusion, lack of communication. When English is not the 1st language, literacy issues, problems of trust between the people themselves and the system, and lack of cultural awareness of their needs.

So I mentioned the 2016 report by the UN. It is helpful to have these reports, because nearly all countries in the world, all 170 countries that have ratified the treaty I mentioned earlier. All of them, every 5 or 6 years go through this process by which the Government needs to submit information to the UN. Committee on economic, social, and cultural rights including on health. And then civil society and academics provides alternative information sometimes called shadow reports. So they respond to what the Government is saying, and then the UN. The Committee engages with civil society and with the government, and they come up with reports called Concluding Observations with their findings and their concerns, and also sometimes the good news of good things that have happened in the country.

Well, the last report is from the year 2016. The next one is going to be in a few months from now in 2025.
So this meeting between civil society, between the committee and the UK Government is going to take place on the 13th and 14th of March in Geneva and the committee is going to use evidence provided by civil society and by academics. And because we have done this work with Gypsies, Roma and Travellers in the East of England, we can submit evidence to the UN Committee. We know that the UN Committee is concerned about access to healthcare and structural discrimination against Gypsies, Roma and Travellers in the UK. As a whole they raised these concerns in 2016. They raised these concerns again when they asked certain questions to the UK Government a few months ago, and we're going to submit the evidence based on this project to the UN Committee. So hopefully, the UN Committee will once again raise these concerns, raise these issues in their reports. The fact that there is a new government gives a new opportunity for the UN. Committee and for NGOs and researchers to engage on these issues with new, fresh eyes, a new perspective. And it's important that the UN Committee highlights and identifies all the reasons of concern in relation to all socioeconomic rights and also health for Gypsies, Roma and Travellers. So we will be submitting the evidence probably next month. As I said, the meeting between the UN Committee and the UK Government will be in March, and we should be expecting the UN reports perhaps 2 or 3 months afterwards, sometime in May or June, and hopefully this will be useful material for those of you holding the authorities to account in relation to health and other social rights.
I will stop here, and happy to take questions or or comments. Thank you.

Question: So what happens then? When that report comes back from the UN? Is there a compulsion on the UK Government to act on that report, or what happens? What comes after the UN come back and say, yeah, based on the evidence you're not meeting those…?

Koldo Casla: So we cannot say that it is legally mandatory. There is no, you know, universal law that says that governments need to apply these reports within, say a year or anything like that. Really, the power of these reports depends on us because there is international relations. Scholars say that we live in a world of anarchy. There is no international government or international police to force governments to do certain things. So that's what they call anarchy. And because we live in this world of anarchy, it depends on us civil society scholars and NGOs to use this report as a helpful reference. It will be a short, comparatively speaking, a relatively short document of, about, say, 15 pages or so and it will contain pretty much all the areas of concern you can think of in relation to socioeconomic rights. And if you can think of any other areas of concern that are not included in the report, then that means that the committee is not doing a very good job, so either everything you can think of in relation to socioeconomic rights will be included, or nearly everything, not with a huge level of detail, because the point is not really to provide all the evidence. It is really to highlight the concerns, and then it depends on us to hold the authorities to account. The last report was very, very unhelpfully published on the very same day of the Brexit referendum in June 2016. So that meant and that was also my first day for working for an NGO. And my job was to ensure that government and public authorities and journalists were aware of this report. Obviously no one was paying attention because everyone was looking at Brexit and and so on. So it was a challenge. Hopefully this time the media, there will be less background noise when the report comes out, and then it will depend on us whether it is implemented or not. I was listening to someone yesterday who said, there is absolutely no reason to be optimistic about anything when it comes to human rights. But there's a reason to be hopeful, and every now and then you get surprises. So, for example, there were 2 things that were included in the 2016 reports that now the new government has pledged to implement- none of them about health sadly, but you know important things nonetheless. For instance, the end of no fault evictions in England is supposed to end with the Renter's Rights Bill and the implementation of the Socioeconomic Duty Section One of the Equality Act. So both of these 2 things were included in the 2016 list of recommendations. It depends on us to hold the

Government to account, to ensure that for the 2025 reports that as many recommendations there as possible are implemented.