Promoting Health Equality in Travelling Communities

A report from the Caring Together project

Norfolk and Suffolk NHS Foundation Trust
About us

Caring Together is a leading charity supporting carers of all ages across Cambridgeshire, Peterborough and Norfolk.

There are over 150,000 unpaid carers across the region covered by Caring Together, and tens of thousands more are caring alone behind closed doors.

More than three in five of us will become an unpaid carer at some point in our life. We will look after a family member or friend who needs our help because of illness, disability, poor mental health or addiction.

Despite how common caring is, many unpaid carers feel they are on their own.

To find out more visit caringtogether.org
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Introduction

Gypsy, Roma and Travellers (GRT) have been identified as one of Britain’s most disadvantaged and marginalized groups, described as having the country’s worst outcomes across a range of social indicators.

The last census showed there were 100,981 Roma people and 67,768 Gypsy or Irish Traveller people living in England and Wales, although other estimates suggest over 300,000 people from Romani and other Traveller groups live in the UK.

In education, national statistics show 19% of Gypsy or Roma pupils, and 26% of Irish Traveller pupils met the expected standard primary school reading, writing and maths in the school year 2018-19 – the lowest percentages of all ethnic groups. GRT children had the highest suspension rates from school (15.28% for Gypsy or Roma pupils, and 10.12% for Irish Traveller pupils), and the most likely to be persistently absent from school (52.6% of Gypsy or Roma pupils, and 56.7% of Irish Traveller pupils). This disadvantage persists into secondary school; only 8.1% of White Gypsy or Roma pupils who attended state-funded schools in England got a grade 5 or above in GCSE English and maths, the lowest percentage of all ethnic groups. Gypsy or Roma (58%) and Irish Traveller (59%) pupils are also the least likely to stay in education after GCSEs, and – at 8% and 9% respectively – the most likely groups to go into employment.

As adults, GRT people are more likely to face socio-economic disadvantage. They are also less likely to own their own home and more likely to have never worked than any other ethnic group in England and Wales.

Unsurprisingly, GRT people also experience health inequalities. Life expectancy amongst GRT people has been variously estimated at around 10-25 years lower than national average (depending on the exact population studied).

The causes of these inequalities are complex. They include systematic barriers faced by those who are nomadic to any extent, alongside discrimination and racism.
Key findings

- Health and social care professionals have a knowledge gap relating to Travelling communities

- Systematic barriers prevent GRT people who travel from accessing primary and secondary care

- Members of the Travelling community face racism and prejudice from healthcare professionals, leading to misdiagnosis and inappropriate care for treatable conditions

- Experiencing a lack of access, mistreatment and culturally incompetent care damages trust GRT people’s trust in health and social care services

- Engaging Travelling communities in health promotion events may be challenging

- A cycle of negative reinforcement exists; a lack of access and damaged trust may lead GRT people to disengage from health and social care services, or necessitate a direct and assertive approach in order to secure appropriate healthcare. However, such approaches may be interpreted as confrontational and rude, reinforcing health and social care professionals’ prejudices about GRT people

- Engaging members of Travelling communities in health initiatives is a lengthy process, requiring expertise, realistic timescales and funding

- There is enthusiasm for change to the current situation from both Travelling communities and health and social care professionals

- Changing the current cycle must begin with changes to the systematic barriers that reduce access and the racism and prejudice Travelling communities face when accessing health services
Health inequalities amongst Travelling Communities

Research consistently shows that GRT people in the UK face systematic barriers in accessing healthcare and are less satisfied with the healthcare they do receive than the general population.\(^{(8)}\) As a result, 14.1% of Gypsy and Irish Traveller people in England and Wales rate their health as bad or very bad, compared with 5.6% on average for all ethnic groups. GRT people aged 65 and over have the lowest health-related quality of life of all ethnic groups (average score of 0.509 out of 1) – the average health of a UK Roma or Traveller person in their 60s is comparable to an average white British person in their 80s.\(^{(11)}\)

Compared to adults from other ethnic groups, GRT adults report less satisfaction with both their access to GP services (56.9% report a positive experience making an appointment compared to 67.4% for all respondents) and their experience of GP services once they have an appointment – only 73.0% say they had a positive experience. Research has shown that although there is no legal requirement to provide an address when registering with a GP Practice, around half of the surgeries investigated would not register someone without an address, creating a systemic barrier for those within Travelling communities.\(^{(9)}\) During the pandemic, researchers found this proportion increased to nearly three-quarters of surgeries included, in direct contradiction of NHS advice.\(^{(9)}\) Similarly low rates of GRT adults are successful in booking an NHS dentist appointment.\(^{(12)}\) Compounding this lack of access, health may be considered an ‘unclean’ subject within some Travelling communities, making discussion with and support from friends and family members more difficult to access.\(^{(13)}\)

At least in part as a consequence of this lack of access, GRT adults experience poorer health than the general population. The rates of those with a long-term illness, health problem or disability which limits daily activities or work is 11% higher than the general population.\(^{(14)}\) This includes a higher prevalence of arthritis (22% vs 10%), rheumatism (6% vs 1%) and heart disease (8% vs 4%).\(^{(14)}\) A higher percentage of GRT people smoke than in the general population,\(^{(15)}\) and there is a higher prevalence of deaths from respiratory diseases and cardiovascular diseases.\(^{(14)}\) There is a higher rate of miscarriage amongst GRT communities than the general population (16% vs 8%), and maternal death rates are higher.\(^{(14)}\) Domestic abuse is also an issue within GRT communities, with estimates that 60%-80% of women from travelling communities experience domestic abuse during their lives.\(^{(2)}\) 28% of GRT adults have anxiety or depression compared to 4% of the general population,\(^{(14)}\) and suicide rates are seven times higher than the general population.\(^{(2)}\)

Children from travelling communities also face disadvantages with their health. Infant mortality rates for GRT children are up to five times higher than for the general population, GRT children have lower average birth weights, lower rates of baby and child immunisation, and are less likely to be breastfed.\(^{(14)}\) As children, they have a higher rates of accidents and are more likely to be identified as having either special educational needs or mental health needs than white British children.\(^{(14)}\) 16% of GRT children are young carers for a disabled or ill dependent relative, compared to 8% of all children, and they are three times more likely to be taken into Local Authority Care than the general population.\(^{(15)}\)
The Project

Caring Together were awarded funding by the NHS Norfolk and Waveney Integrated Commissioning Board to undertake work to address the health inequalities of the wider Travelling community in Norfolk. The project consisted of two main strands – work with health and social care professionals, and work with members of the Travelling communities.

Caring Together have previously undertaken work with Carers from GRT communities in Cambridgeshire. In 2022, they were awarded funding to carry out a similar project addressing the health inequalities faced by all Travelling communities in this area. The area is of significance as it is estimated that around 24% of the UK’s pitches are in the East of England. There are around 180 pitches in Norfolk and Suffolk counties – the vast majority of these are in Norfolk alone.

Aims and objectives

In line with the NHS Long Term Plan and national drivers, the project’s aim was:

To promote improved physical and mental health and reduce poor health outcomes within the travelling community.

The detailed objectives of the project were to:

- Coproduce ways to create health equality within the travelling community
- Develop ways to support those populations who travel into Norfolk and Waveney.
- Promote good physical and mental health
- Discover how to make services more accessible to this community

Work began with gathering coproduction partners to develop this thinking, alongside consultation with Travelling community members.
Health and social care professionals

Co-production partners were gathered together in a project steering group, and included:

- Norfolk County Council Prevention Policy Manager
- Researchers from Essex University,
- Norfolk and Waverley ICB Learning Disability support workers
- Broadland Housing Association Traveller Site managers
- Norfolk Virtual School GRT lead

A focus group was held, attended by the organisations above as well as other health and social care professionals. In total 26 professionals register to attend. The purpose of the focus group was to gather knowledge about local health inequalities and barriers from professionals who currently worked with local Travelling communities and consider how this knowledge could be transmitted to those who wanted to work with community but were facing barriers. The focus group was able to highlight some of the main barriers to successful engagement. From the point of view of professional engagement the focus group highlighted that the two major barriers were that – whilst many professionals wanted to work with local Travelling communities - they but were either:

1. Fearful of making mistakes in their approach, or
2. Lacked of awareness of the needs of the communities

As a direct result of the focus group, cultural awareness sessions were planned for health and social care professionals. Caring Together recruited a ‘by and for’ partner organization to deliver the sessions, who specialize in working with GRT communities and whose workforce is made up of at least 50% GRT community members – Friends Families and Travellers.

They created and planned a series of six cultural awareness sessions for health and social care professionals. The sessions aimed to upskill health and social care professionals, provide information about the travelling communities, and to develop GRT cultural competence within services. The maximum audience for each session was 30, and the six offered sessions were fully booked within four working days. Caring Together therefore arranged an extra two sessions – offering a total of eight sessions which reached 240 professionals. These sessions included a brief history of Travelling Communities, alongside information about traditions within different communities which had a bearing on health. They then examined barriers to engagement and potential solutions to these.

In November Caring Together organized an in-person conference at the University of East Anglia. The conference was attended by 28 professionals attended whose professional remit included working with the Travelling communities within the project area, such as Traveller Site managers, health visitors, and those within public health and mental health services. The conference provided an overview of the health inequalities and the work Caring Together had already completed. The co-produced video resource was also shown. The conference ended with a roundtable discussion of the next steps towards promoting health inequality in local Travelling communities. Positive feedback was received from this event, with the prominent role given to community voice being viewed especially favourably.
Engagement with travelling community members

Drawing on the expertise of the steering group, a direct approach to recruiting members of Travelling communities was employed. Professionals with existing connections to the communities were asked to distribute information about the project to their connections – an adaptation of snowball methodology. (16) Link building with the community was slow. In part, this was due to lockdown, as services who had previously had face-to-face contact with the community had reduced contact. Some services, such as GRT Service, Inclusion and SEND who had previously conducted visits to local Traveller sites had not resumed site visits after lockdown ended.

Some difficulties in identifying those who could assist in recruitment were also encountered, as there is no centralized information about existing Traveller sites, their locations, or information about which sites are run by or on behalf of the Local Authority, and which are private sites (recruitment via private sites was deemed unethical). Difficulties were also encountered whereby some managers at sites run by or on behalf of the Local Authority did not have good relationships with the Travellers on the sites. One manager had very good relationships, and was able to recruit a number of community members to be interviewed by the project. Individual interviews were held, with 9 members of the community, to identify the key issues that affected their health.

Following on from the interviews, a Family Day was planned. The day was intended to be a knowledge exchange event, where issues raised in the interviews could be discussed further, and information about health issues could be provided. A flyer for the day is shown here.

Despite carefully planning the day in conjunction with Travelling community members, the event was not attended by any GRT people. Discussion with community members later identified that one difficulty for community members was that they didn’t know who else would be attending. Future events of a similar nature may be more successful if a travelling event is planned on each specific site.
Goodie bags initially intended for distribution at the Family Day were later distributed to individuals at Traveller sites, in part by the site manager from Broadland Housing Association. The goodie bags included information from:

- NIHR (Clinical Research Network Eastern) Rebo’s Research Adventure! Play our game and help Rebo, the NHS Research Robot, find treatment for diabetes!
- NHS Wellbeing service
- Just One Norfolk
- The Matthew Project
- Breast Cancer Now - The research and Care Charity
- Norfolk and Suffolk Foundation Trust
- Carers Matter Norfolk
- The Health Improvement Team – information around annual health checks
- One Call Away -ASIST – Gypsy/Traveller/Depression/Suicide – confidential support service.
- Norfolk and Waveney Children and Young Peoples Health Services
- Norfolk County Councils Guide to Care and support for Adults
- Speak up against Adult Abuse Norfolk Helpline
- Norfolk and Waveney Integrated Care System – Transforming Care Navigators for Children and Young People in Norfolk and Waveney
- NCC/Shaw Trust – Norfolk Connect Youth Support Service
- Tapping House
- Emergency Planning – Caring Together
Working with members of the community, Caring Together produced a video highlighting real life experiences of health inequalities and experiences of prejudice faced by members of the Travelling community when accessing health services. This was used in HCP conference.

As one of the aims of the project was to directly improve the health of members of the Travelling community, small bursaries were made available to community members for anything that might directly impact their health. Implementing the learning from the Family Day, information about this funding was distributed directly to members of the community via professionals who had existing positive relationship with the local communities. An example of the flyer is shown below.

Uptake of the funding was good, with 14 bursaries made to the total of £5037.20 to benefit 57 families. Two examples of the bursary use are below:

One person had been living off takeaways due to poor mental health. This did not provide an appropriate diet and his physical health was suffering. The site manager arranged for Meals on Wheels to deliver food, and a bursary paid for a microwave so he could reheat the meals.

A group of residents were all experiencing breathing difficulties. Drying laundry on airers in a small space was identified as having a negative impact on their breathing. A bursary provided a tumble drier which helped to improve their health.
Analysis methodologies

A range of data were available for analysis. Most of the data was of a qualitative nature, with some quantitative elements, therefore a mixed methodological approach was employed. Simple A brief explanation of the methodological approach employed is presented below.

Quantitative analysis methods
A total of 240 health and social care professionals attended cultural awareness sessions. Of these, 35 provided feedback. As the number of participants was small, quantitative data is reported in a descriptive form with no further quantitative analysis. [17]

Qualitative analysis methods
The qualitative dataset included feedback from the cultural awareness sessions, mindmapping from the conference and interview data from Travelling community members. Most data was in a written format, the video interview used at the conference was in audio-visual only format. These data were thematically analysed. [18] Thematic analysis is a methodology commonly used within health research and can be used to analyse a wide range of data from disparate sources. Reflexive thematic analysis consists of a series of six stages:
1. Become familiar with the data
2. Generate initial codes
3. Search for themes
4. Review themes
5. Define themes
6. Write-up

All qualitative data supplied by Caring Together was read/watched and re-read/re-watched by the researcher multiple times before coding began. Codes were recorded manually rather than in qualitative software due to the the multi-media nature of the data.
Detailed findings and discussion

The findings are presented below, alongside a discussion of the implications that arise from them.

Quantitative findings
A total of 240 health and social care professionals attended cultural awareness sessions. Of these, 35 provided feedback. As shown in Figure 1, there was a good distribution of feedback from different sessions.

![Figure 1 – dates of session attended by those providing feedback](image)

The feedback from the cultural awareness sessions was largely positive. A 5 point Likert scale was used to measure attendees overall view of the cultural awareness session, and the feedback was largely positive. As shown in figure 2, 26 participants (74.3%) rated the session they attended as very good and 7 (20%) rated it as good.

![Figure 2 – overall view of the session](image)

When asked whether they would recommend the session to others, 33 participants (94.3%) said they would, with 2 (5.7%) saying they would not.
Qualitative findings

The feedback from the cultural awareness sessions, mindmapping from the conference and interview data from Travelling community members were thematically analysed. (18)

Six major themes emerged from the thematic analysis. These are shown in table 1, and the sources of the theme are detailed.

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<td>Community interviews, Focus group</td>
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<td>Racism and prejudice</td>
<td>Community interviews, Feedback from cultural awareness sessions</td>
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<td>Lack of healthcare professional knowledge about Travelling communities</td>
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<td>Cycle of reinforcement</td>
<td>Community interviews, Focus group, Feedback from cultural awareness sessions, Conference mindmapping</td>
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<td>Engaging Travelling communities is a long process</td>
<td>Community interviews, Focus group, Conference mindmapping</td>
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<tr>
<td>Enthusiasm for change</td>
<td>Community interviews, Focus group, Feedback from cultural awareness sessions, Conference mindmapping</td>
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Each theme is described in more detail below.

**Lack of access**

Health services which require someone to have a fixed address exclude GRT people who still travel. This may lead to GRT people either facing difficulty in accessing, or being entirely unable to access healthcare services. This includes not only GP services, but dentists, opticians and family planning services. Interviewees gave examples where they or family and friends had been denied access to a service, or had experienced difficulty in gaining access to services. Without access to primary healthcare services, Travelling community members may also be unable to access specialist services and therefore may not receive appropriate care for treatable conditions, leading to poorer health and premature deaths. One interviewee reported:

‘There’s a lady who just died. And she died cos she had womb cancer. She never had a doctor’

Even once registered with a service, GRT people may experience structural barriers to accessing health services. There are lower rates of literacy amongst Travelling communities than in the general UK population, yet accessing health services may require advanced literacy skills in order to complete forms, make appointments and understand health information. Fieldnotes from the interviews detail an example of this:

‘If it wasn’t for the health visitors help and support the paperwork would have been like a puzzle as she cannot read and write’
Racism and prejudice
Members of the Travelling community experience racism and prejudices some from healthcare professionals which impacts their access to health services and consequently their health. One interviewee reported that despite the fact he was experiencing chronic pain following surgery to his knee,

‘the doctor told him that he wouldn’t prescribe pain killers as he believed he would sell them on his site’

GRT parents in particular may face additional barriers in accessing healthcare for their children. GRT parents’ reported that some healthcare professionals dismissed their concerns, leading to misdiagnosis and the missing of serious and even life-threatening conditions. They also reported that even when a correct diagnosis was given, healthcare professionals had told them that their ‘lifestyle’ is the cause of the illness. An interviewee reported being present when a family member was told:

‘How you’re living, that’s why [your child] has impetigo’

A further difficulty arose when healthcare professionals assumed accidental injuries were the result of neglect or domestic abuse. An interviewee reported the fear she felt when a healthcare professional believed injuries sustained during a normal childhood accident were the result of her child being abused:

‘I was so so scared that they were going to take my child away from me. I was so worried I vomited where I stood. Even though I knew it wasn’t true, what they were saying happened, I’ve seen it so many times with Travellers.’

As can be seen from the statistics about the over representation of GRT children within the Care system, this fear is based at least partially in reality. Stress is a known risk factor for poorer health outcomes – if encounters with health and social care professionals are stressful, interactions have the potential to increase health inequality.

GRT people’s experiences of racism and prejudice were affirmed in the feedback received from health and social care professionals who had attended the cultural awareness sessions:

‘Q5. How will the training impact your work with Travelling communities?
   • I have a better overall grounding in the facts about gypsy and traveller communities which will help me challenge prejudices and misconceptions I have noticed colleagues expressing.’

Whilst community members also reported some examples of excellent care, the experiences of culturally incompetent care, racism and prejudice damaged trust in all health and social care professionals.

Lack of healthcare professional knowledge about Travelling communities
Interviewees reported numerous examples of incorrect assumptions which healthcare professionals made about what life is like as a member of the Travelling community, whether settled or still travelling. Most centered around assumptions that GRT people had lower hygiene standards than other British people.

These reports of a lack of knowledge amongst professionals are corroborated by the feedback from the Cultural awareness sessions, as the comments below show:

‘Q4. What did you find most useful?
   • Getting an understanding of the various types of travellers
   • All of it was useful and really opened my eyes to the challenges faced by this community
   • The insight into their culture and how the culture clash has created barriers that we wouldn’t think about’

One feedback response to the cultural awareness sessions stood out:

‘I am the champion for the GRT community in my job and I am new to this role. Training today has given me a really clear guidance of barriers, and what is acceptable in the GRT community and what is not, so this has helped as I do not want to offend anyone.’
Whilst it is positive that the person was able to access the training, it is of some concern that an individual could be allocated as a champion for the GRT community without already having reasonably extensive knowledge about the community. This comment therefore reflects the knowledge gap that exists.

**Cycle of reinforcement**

When healthcare professionals make incorrect assumptions about GRT people’s lifestyle, or misdiagnose health conditions, GRT people’s trust in healthcare professionals is damaged. In order to secure appropriate care, one interviewee described forcefully declining care from a specific doctor who had previously misdiagnosed her child. This appears to reflect a wider necessity for GRT people to be very assertive in order to secure appropriate access to healthcare. There is a wide body of literature demonstrating that health professionals find it challenging to form relationships of care with patients who they perceive as uncivil, demanding or rude, labelling them instead as ‘difficult patients’ and providing either suboptimal care, or care which is uncaring. (19–23) The categorization of one GRT person as a ‘difficult patient’ may result in professionals who have a knowledge gap labelling all Travelling communities as potential difficult patients, creating in turn a further barrier for GRT people who wish to access health services. This cycle is shown in figure 3.

**Figure 3 – cycle of reinforcement**

[Image of a cycle diagram showing the cycle of reinforcement]

Engaging Travelling communities is a long process

Historic mistreatment and exclusion combined with current barriers to access and open prejudice against GRT people mean that engaging Travelling communities in health initiatives is a challenging task. When combined with cultural values that may make general health (and mental health in particular) a difficult topic to discuss openly and a lack of widespread professional understanding about these cultural values, engagement work cannot be undertaken rapidly. Following the lack of community attendance at the Family Day, feedback from a health professional articulates this understanding:

‘Getting people from Gypsy, Roma, and Travellers communities to engage presents particular challenges in view of their discrimination, and rejection by mainstream society’

The solutions to this challenge are indicated in the mindmapping from the conference:

- More education and training for professionals
- Human to human contact
- Building trust
- Listening to the community

Building trust between Travelling communities and health initiatives must begin with ensuring that the current
A professional knowledge gap is addressed before trust can be built. Building trust with communities which have faced significant exclusion is a precursor to successful engagement work. Therefore projects which seek to engage Travelling communities in health initiatives must have realistic timescales and resources attached to them to allow both these stages to be completed before engagement work can be successful. Initiatives which are insufficiently resourced or have short timescales are likely to not only be unsuccessful, but to further damage trust.

**Enthusiasm for change**

Very positively, both members of the Travelling community and health and social care professionals expressed enthusiasm for changes to the current situation. After numerous doctors dismissed her concerns about her child (who had pneumonia, meningitis and a severely compromised immune system), one interviewee described an experience with one doctor who took her concerns seriously and who provided appropriate care. After receiving appropriate care from him, she said:

‘I refused to see any other doctor. He listened.’

This demonstrates the potential for appropriate and trusting relationships to be built.

Health and social care professionals who attended the cultural awareness sessions were also enthusiastic about the learning they had acquired and keen to implement it:

**Q4. What have you found most useful?**
- Practically speaking, the point raised about how WhatsApp could be used to send voice notes and photos was very pertinent to my work. We are currently looking to introduce new communications methods to enable us to reach more families to offer our support service.

**Q5. How will the training impact your work with Travelling communities?**
- It’s made me question how we can be more proactive with travelling communities, ensuring that our services are available and inviting
- I will be more conscious that families from traveller communities may not describe mental health difficulties in those terms
- Will help me plan my interventions with families and give me a broader insight to sensitive issues and understanding of how travelling life is for folk.
- Will guide different ways to approach outreach/engagement

**Q8. Any other comments?**
- Having a section on barriers to help and how to help overcome them was really helpful

Numerous further examples of changes that participants could personally implement were provided. Mindmapping from the conference set out potential steps towards changes towards wider practice and structural changes, designed to overcome the current barriers to achieving health equality for Travelling communities. These suggested next steps have been combined with knowledge from the professionals involved in the steering group and findings from the literature to produce a series of recommendations to move towards this goal.
Recommendations

This project shows that the desire for changes to improve the health of Travelling communities in Norfolk is high amongst both health and social care professionals and Travelling communities within Norfolk.

It highlights some of the barriers which currently obstruct this work, as well as providing evidence which may guide further work towards health improvements. However, as the national picture of the health inequalities faced by GRT members show, considerable work is required to make the systematic and organizational culture changes that will reduce health inequalities. It is crucial therefore that the work begun by this project is continued into the future and that the findings are given due attention by the policy makers and practitioners within local health and social care services. To facilitate this, the following is recommended:

**For health and social care services:**
- Undertake an audit of any systematic barriers which might prevent access by members of the Travelling communities, such as requirements to have a fixed address, or to communicate in a particular format (especially written)
- Roll out Cultural Awareness training about Travelling communities
- Explicitly include GRT people in any equality statements
- Ensure suitable categories for GRT people are included as ethnicity options in diversity monitoring for both workforce and service users
- If people from Travelling communities are not accessing your service, consider asking those who do access the service, or others with expert knowledge about the community, what the barriers might be. Remember that Patient and Public Experts should be appropriately compensated for their time

**For health and social care practitioners:**
- Access resources and training to improve cultural competence in working with Travelling communities
- Use a variety of formats for communication, consider using voice messaging where possible
- Visit GRT people at their homes rather than making appointments where they visit the practitioner

**For regional organisations:**
- Establish a centralized list of authorized publicly managed Traveller sites, including contact details for site managers, accessible to public and third sector health and social care partners, and keep this list up to date
- Establish a regional group of those who work with the Travelling communities in the region to advise about improvements to service access
References


