

# Gypsy, Romany and Traveller communities

## The impact of the Covid-19 pandemic

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## 1. Introduction

There are growing concerns around the world about disparities in the impact of the Covid-19 pandemic, in particular higher rates of infection and mortality amongst some ethnic groups. A recent review of the evidence of disparities by Public Health England (PHE) found an association between belonging to some ethnic groups and the likelihood of testing positive and dying with COVID-19 (PHE, 2020a<sup>1</sup>). The review highlighted that:

- the highest age standardised diagnosis rates of COVID-19 per 100,000 population were in people of Black ethnic groups (486 in females and 649 in males) and the lowest were in people of White ethnic groups (220 in females and 224 in males).
- after accounting for the effect of sex, age, deprivation and region, people of Bangladeshi ethnicity had around twice the risk of death when compared to people of White British ethnicity.
- People of Chinese, Indian, Pakistani, Other Asian, Caribbean and Other Black ethnicity had between 10 and 50% higher risk of death when compared to White British.
- Death rates from COVID-19 were higher for Black and Asian ethnic groups when compared to White ethnic groups. This is the opposite of what is seen in previous years, when the all-cause mortality rates are lower in Asian and Black ethnic groups.

Differences were also found by gender, for example compared to previous years, all-cause mortality was:

- almost 4 times higher than expected among Black males for this period;
- almost 3 times higher in Asian males;
- almost 2 times higher in White males.
- Among females, deaths were almost 3 times higher in this period in Black, Mixed and Other females, and 2.4 times higher in Asian females compared with 1.6 times in White females.

There are limitations in the evidence, for example the data did not account comorbidities such as or obesity, and when these are included, the difference in risk of death between ethnic groups among hospitalised patients is greatly reduced. While more needs to be done to understand the associations with ethnicity and the risks and vulnerabilities for Covid-19, what is known is that the pandemic has exacerbated long standing inequalities.

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<sup>1</sup> PHE (2020a) Disparities in the risk and outcomes of COVID-19. London: PHE

The poorer socioeconomic circumstances of some Black, Asian and Minority Ethnic groups are linked with poor health outcomes and underlying prevalence of long-term conditions including obesity, diabetes, hypertension and heart disease and mental health problems.

Economic disadvantage and the associated marginalisation and hardship increases the risk of vulnerability to disease and is very likely to be a significant factor in the disparities that have been identified for different ethnic groups. Unfortunately, the PHE data subsumes Gypsy, Roma and Traveller (GRT) into the category Other white, which masks the impact of the pandemic on these communities:

*“Smaller ethnic minority groups such as the Gypsy, Roma and Travellers...are missed by current ethnicity recording.” (PHE, 2020b<sup>2</sup>)*

It is not satisfactory to dismiss entire communities from the evidence base due to lack of ethnic recording. There is lived experience data from GRT communities that shows the pandemic is having a profound detrimental impact. The failure to pay attention to this and ensure that the experiences of GRT communities are included in national and local responses to the pandemic risks leaving whole communities without adequate support and help and may also result in the virus spreading further in these communities.

With the support of NHS England and Community Innovations Enterprise, GypsyLife who are an independent, Gypsy, Roma and Traveller community group with extensive experience of providing health advice and support to GRT communities across England, have captured the lived experiences of community members while they try to cope with the pandemic.

This report provides feedback from these data, which have been gathered through interviews and surveys involving 1150 individuals. The data is largely qualitative, though where possible quantitative analysis has also been undertaken. The report first presents the data group according to key themes and issues that have been identified using constant comparative methods to identify core categories of risk and vulnerability. At the end of the report a series of recommendations are made that focus on the immediate and short-term needs and longer-term change that is required to prevent future health harms.

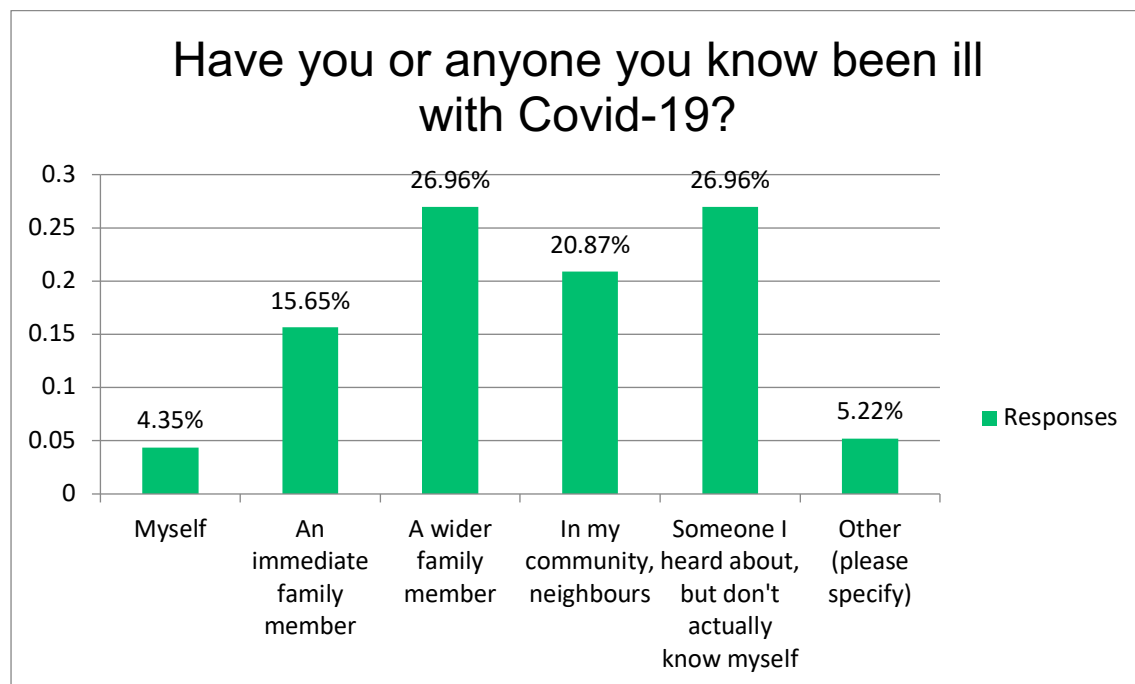
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<sup>2</sup> PHE (2020b) Beyond the data: Understanding the impact of COVID-19 on BAME groups. London: PHE

## 2. Spread of the virus in the community

The reported spread of the virus across GRT communities is high. For example:

- 16% report having an immediate family member who has the virus and 27% report having a wider family member who has the virus
- 27% know someone in the wider GRT community who has the virus and 21% someone in their immediate community and neighbors
- 4% of respondents report having the virus themselves



### 2.1 Social distancing

The risk of the spread of infection in the community has been greatly affected by problems with social distancing, in particular on sites. For example, some site owners were said to be causing tensions and problems by not ensuring that social distancing was adhered to properly:

*“The site owner is not following social distancing and letting people in and off site.”*  
(Survey respondent)

Respondents also identified problems with social distancing as a result of cultural and lifestyle factors, for example living in tightly managed communities with close family ties. Trying to adapt to social distancing has had a disturbing impact on how people feel about their culture and community:

*“It’s been very hard to stick to the guidelines as it goes against our culture not to be there for each other, I have been left feeling empty and hollow, now I have to find a new way of carrying on through life.”* (Survey respondent)

If someone in the family has become ill, there are concerns that it is not possible to isolate them from other people:

*“I’m coping badly, my husband came down with a fever and a cough, guidelines say he should self-isolate, how can he do that when we only have two trailers - one for four children and then the two babies are in our trailer? So, there’s eight of us already overcrowded in two trailers. It simply isn’t possible to do that.”* (Survey respondent)

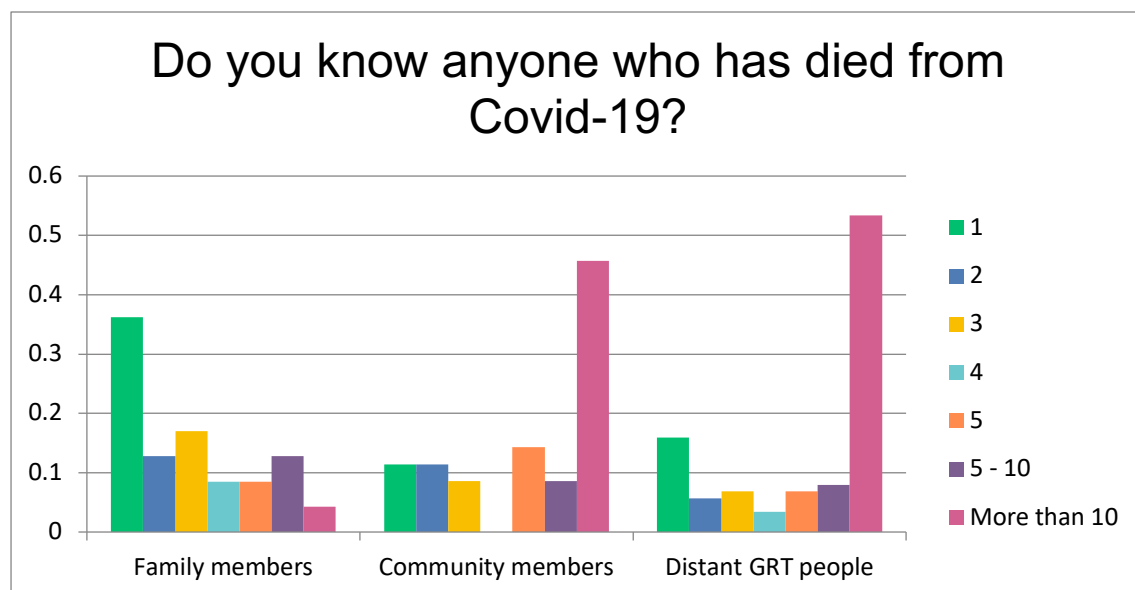
Other practical problems with maintaining appropriate social distancing included lack of toilet facilities, for example on one site there were only two toilets for 200 people.

People were also unsure about the correct way to do things, for example people heard about the bubble plans but did not know if this meant they could mix freely on the site.

### 3. Mortality

The numbers of people know who have died from Covid-19 are reportedly high, for example:

- 2 report more than 10 family members having died (equivalent to 20 people)
- 16 people report knowing more than 10 community members having died (equivalent to 160 people)
- 47 people report knowing more than 10 distant community members who have died (equivalent to 470 people)



The total number of deaths from Covid-19 known to the sample was 981, which is an average of 8.5 people per person.

### 3.1 Dealing with grief and bereavement

Dealing with bereavement and grief is one the most difficult things that respondents have been dealing with. In particular:

- Feeling **unable to grieve fully** due to the restrictions on funerals. Funerals are often very large events for the GRT community, with sometimes 100's of people attending, and families have struggled a great deal with the very limited number of people that can attend a funeral:

*“Not being allowed to support the family because of the small numbers at funerals. This will leave a terrible impact on all of us.”* (Survey respondent)

*“It’s awful. I can’t cope with isolation and not people able to support people I love and care for, we are a face to face community. Not being there for anyone is causing conflict in the family, because a lot don’t understand the Covid restrictions, so they just assume you’re heartless.”* (Survey respondent)

*“I’m not coping, I feel heartbroken. I lost my child and can’t have a proper funeral, can’t bring him home, I’ll never ever get over this, this pandemic is ripping the world apart in ways in never thought I see.”* (Survey respondent)

- The high number of deaths known to the community has produced a **heightened sense of fear about risks** and who might be vulnerable.

*“All I am hearing about is death, young and old ...not being allowed a proper funeral and you can’t support anyone through fear of catching the virus and dying yourself. I can’t think about anything else other than death. And to top it all my husband is in jail, haven’t seen him in months right now I just need to be with my family.”* (Survey respondent)

- Hearing about deaths in other GRT communities through **social media** has left people feeling that the pandemic is running through the community unchecked.

*“Every time I go on my social media there are more and more people passing away, it’s hard to keep seeing the GRT death toll rising and the community are feeling forgotten.”* (Survey respondent)

*“Another cousin passed away today, four months after her sister. Both young women, both with families.”* (Survey respondent)

- People have struggled when someone is in hospital and being unable to be with them. Some have also reported being asked to sign **DNR notices** without fully understanding what is being asked or being able to read the forms due to **low levels of literacy**.

*“My brother went into hospital with a cough, nothing more than that and died alone without anyone there...I know loads of people in my community that’s died Of Covid 19. I’m not sure that we are being told the truth, I can’t stop thinking about those people passing away on their own, it’s not the way we do things in our community we are being forced to sign forms that say do not resuscitate... we are being forced into signing a death warrant, that’s not what hospitals are there for. People who can’t read and don’t understand what the form means, are not having this explained. This is what’s keeping me awake.”* (Survey respondent)

- **Family tensions and arguments** have increased due to the restrictions and having to decide who can be with someone who is dying.

*“Couldn’t support my mother, wasn’t allowed at the hospital, no proper funeral or last journey, no closure for the family having to explain to young children that Grandad is dead.”* (Survey respondent)

*“It’s changed every part of my life, it’s took away my ability to socialise, it’s took two lives of people I love and respect I am left feeling sad and broken, it’s killing my community, my culture and my whole way of life, I’m devastated and I’m not the only one who feels this way.”* (Survey respondent)

*“Because I was unable to visit my elder family during lockdown, they have said they don’t want to talk to me, which is ridiculous, all I’ve done is follow Covid regulations, now I feel I’ve been disowned.”* (Survey respondent)

- While the deaths from Covid-19 are very high in people’s minds, these are viewed as taking place against a **longer-term experience of premature death** in the community either due to long term health conditions or the high rates of **suicide**:

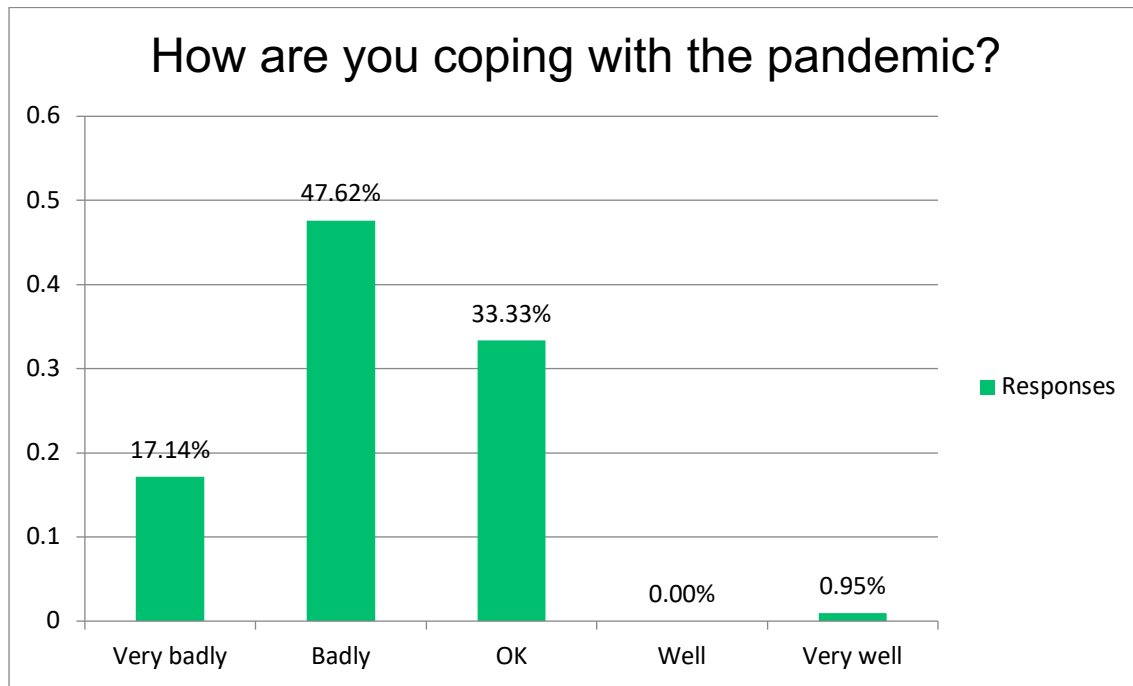
*“The amount of premature deaths both my immediate and extended family have endured is horrendous, in the past five years alone there are almost too many to count. No Traveller family is given time to grieve before there’s another loss.”* (Survey respondent)

*“There are so many young people taking their lives because they can’t cope with the isolation.”* (Survey respondent)



## 4. Resilience and coping

When asked how they were coping with the pandemic, the majority (47.6%) said badly and a further 17% said very badly, with only one third feeling that were coping ok:

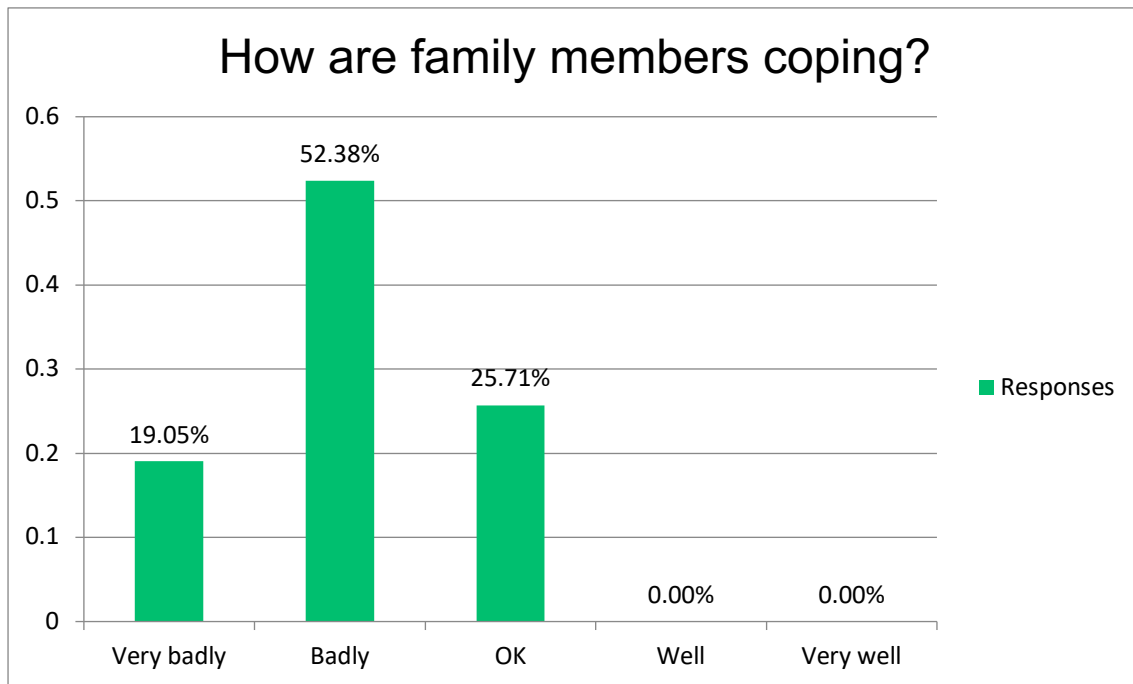


Some of the main reasons people cited as causing them most difficulty included:

- Not being able to see family members and friends
- Struggling with feeling isolated and cut off from normal activities and lifestyle, especially being able to travel which is such a central part of the culture
- Handling grief and feelings of guilt if someone they care about has become ill or died and feeling unable to help
- Worry and anxiety about the impact on children
- Loss of income and employment and anxiety about coping financially

There is a sense that people are losing resilience in the face of the burden of illness and lack of knowledge and awareness about how to manage this.

When asked how other family members are coping, the concerns are higher, for example over half (52.4%) felt that other family members were coping badly and 19% that they were coping very badly:



The main concerns were about older family members, especially if they lived alone in a house and could not be visited, but also money and financial stress:

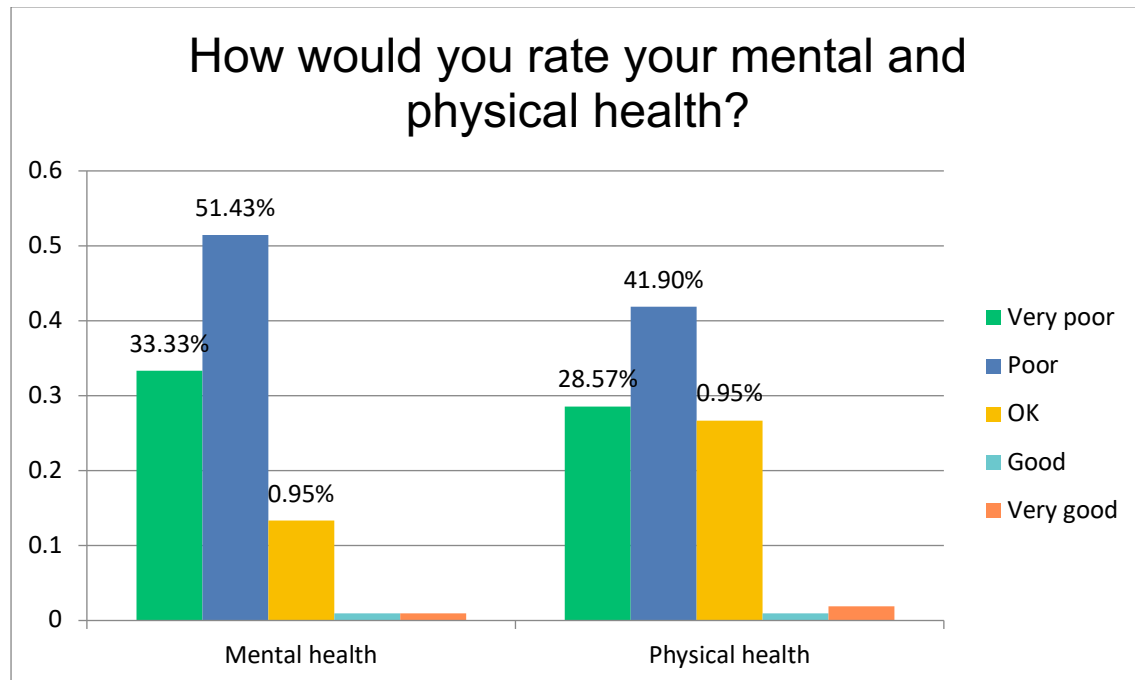
*“Some are coping, some are not, the young are just going about life as normal, but the elderly are very lonely without having visitors, it’s just not our way of doing things. It’s making my nerves bad not knowing who to listen to.”* (Survey respondent)

*“Nana is not coping as she has been in isolation since March.”* (Survey respondent)

*“...money is tight, we can’t earn money in this climate.”* (Survey respondent)

## 4.1 Mental health and wellbeing

Respondents were asked to rate their current physical and mental health. Over half (51.4%) rated their mental health as poor and a further third (33%) as very poor. 42% rated their physical health as poor and a further 28.6% as very poor:



The largest mental health impacts that people describe are worry, lack of sleep and heightened anxiety:

*"I'm frightened all day and night bad with nerves."* (Survey respondent)

*"Worried about everything all of the time."* (Survey respondent)

*"Can't sleep, all I am hearing about is people dying alone in hospital I'm very frightened."* (Survey respondent)

Respondents spoke about experiencing mental health problems including anxiety, depression and an acute sense of loneliness and isolation:

*"Everyone I know is struggling to cope with social distancing and isolation especially the elderly people that are in bricks and mortar."* (Survey respondent)

Drinking more alcohol was also mentioned a main coping mechanism:

*"I don't understand what I can and can't be doing, feel anxious and struggling to sleep, drinking lots more alcohol than ever to help me sleep afraid of being around people."* (Survey respondent)

*"Not sleeping, drinking alcohol to numb worry."* (Survey respondent)

Excessive drinking was viewed as having a detrimental impact on both physical and mental health, but people also reported smoking more, eating poorly and missing medical appointments all of which were impacting on physical health.

## 4.2 Practical help

The practical reality of living on a site causes people a lot of stress, especially if it is overcrowded as many unofficial sites are and there is an absence of proper sanitation. Alongside the practical problems, people are afraid of causing offence to others and there are added financial problems as a result of lost income:

*“It’s hard enough being a traveller but this pandemic is crucifying our culture and everything it stands for, we live in a small trailer on an overcrowded site, there’s hardly any toilet and shower facilities. Everything is shared, you have to bleach all the things before you use them just in case someone has Covid, then your causing offence to others on the site when you go after them. You can’t get help with money or anything, no help with rent payments and that’s all before you start thinking about your own health.”* (Survey respondent)

### 4.2.1 Help with medications and doctor appointments

Restrictions on travel meant that some people were a long way from their doctor or usual hospital and people were unsure how to or felt unable to get their medications or arrange a new local hospital appointment:

*“I was on a site 50 miles away from my home travelling and lock down started; I wanted to go back home, but was not able, missed my appointments with Dr’s and hospital as wasn’t allowed to travel back home.”* (Survey respondent)

*“I was living on a site when lock down started, my doctor is 70 miles away and I have regular medications that I need.”* (Survey respondent)

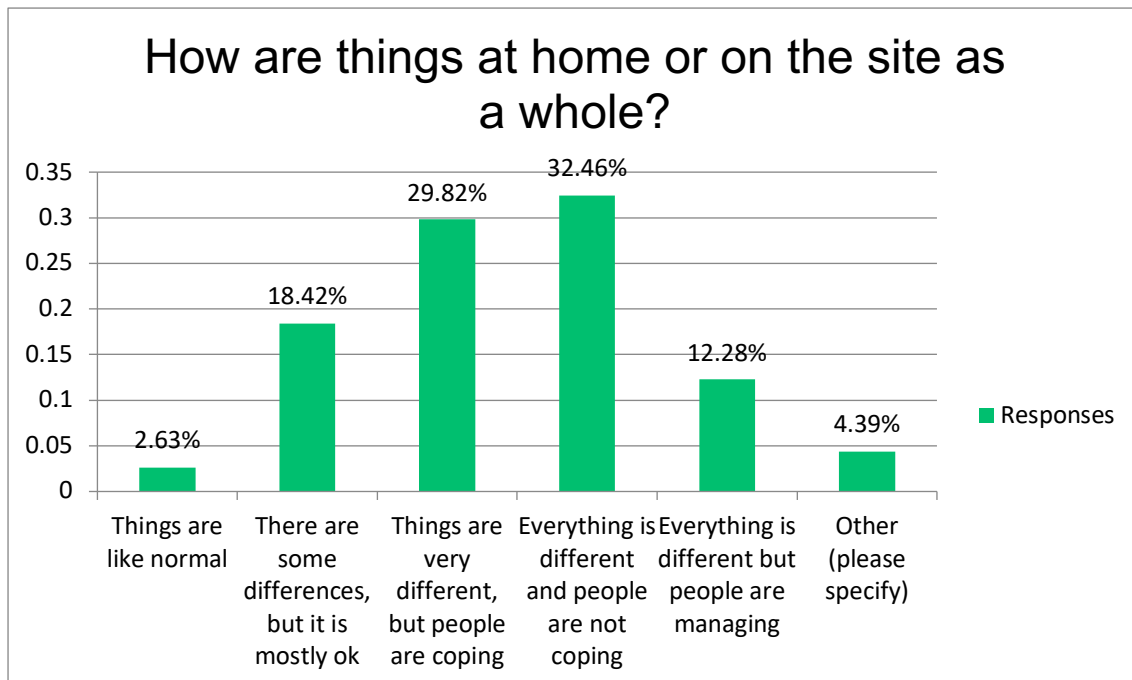
This trend is concerning as it indicates that there may be a build-up of medical and health problems as people have not been able to continue their usual treatment or gain access to medications.

People struggled to understand how they could gain an emergency local appointment with a GP surgery and in some cases were being told that no new patients could be seen.

## 4.3 Community tensions

While the impact on individuals and families is clearly taking a toll, there is some evidence of community resilience. For example, just under one third (30%) report that, although things are very different people are coping and just over 18% say that while there is some difference it is mostly ok.

However, one third (32.5%) do report that everything is different, and people are not coping.



Tensions, especially on sites where people had been locked down together were reported to be high and rising. People felt trapped, sometimes with other family groups who did not get on well, which could lead to fighting and fall outs:

*“The site is like the end of the world, people are arguing and falling out fighting, I’m trapped here and it’s like a war zone.”* (Survey respondent)

*“Everyone is falling out in site, it’s a scary place to be.”* (Survey respondent)

People also feared repercussion if they became ill, for example the threat of being thrown off the site where they were staying:

*“I’m frightened of getting kicked of the site that I’m on because I’ve developed a cough, I can only go out once a week to the shop for a phone voucher that’s the site rules, the doctors aren’t doing appointment it’s phone appointments only, not seen my family in months, I feel isolated and frightened that I could end up dying and only my wife can bury me and I can’t have a proper send off.”* (Survey respondent)

### 4.3.1 Contact with the police

One aspect that respondents thought was leading to increased community tensions was contact with the police. One fifth of respondents said there had been an increase in contact with the police since the pandemic started. The reasons cited included:

- Checking that people were adhering to the restrictions
- Stop and search
- Called out due to fighting and drunkenness on the site

Some reported being unfairly moved on or told to return to the site when they were out shopping legitimately:

*“We got moved on by the police, it was horrible we was escorted out of the town.”*  
(Survey respondent)

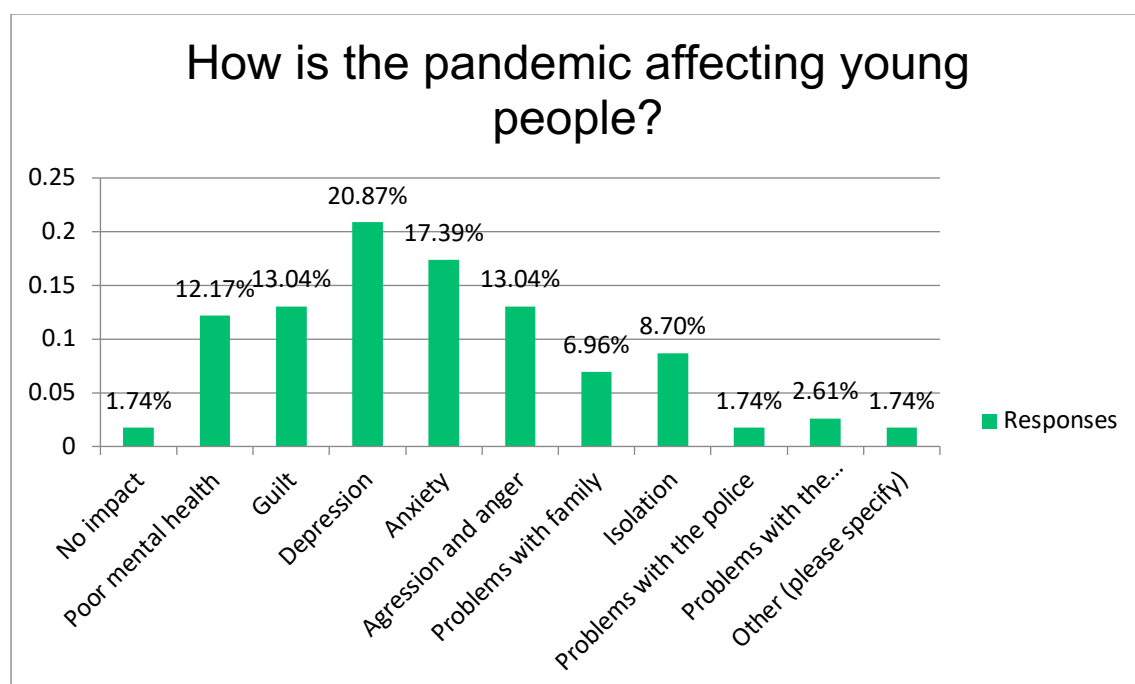
*“I went to get some shopping and got sent home by the police.”* (Survey respondent)

A few reported positive contacts with the police, which they found helpful:

*“They came to check on us on the encampment and they were very kind and helpful they brought in all the services to organise sanitation and left their details in case we got any trouble from anyone.”* (Survey respondent)

### 4.3.2 Concerns about young people

Various concerns have been expressed about the impact of the pandemic on young GRT people including depression, anxiety and guilt:

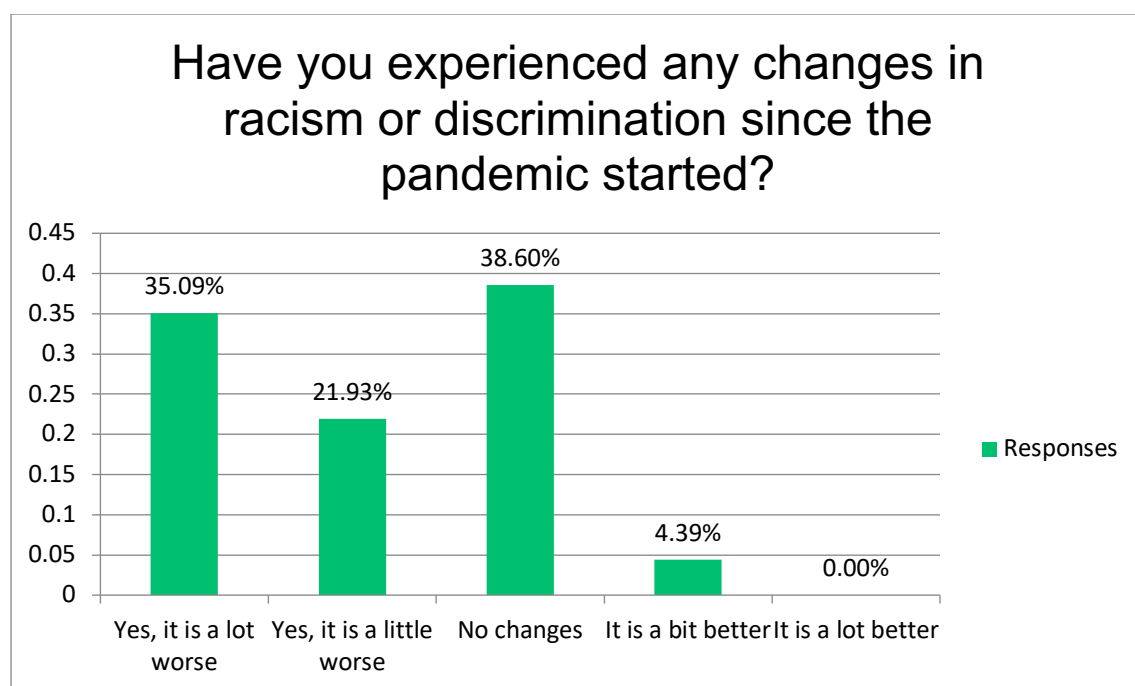


There are also concerns about young people, who are reported to be drinking and using drugs more:

*“The family are coping terribly, isolation is going to kill people, the young are blaming themselves and hitting the drink and drugs, people are not isolating.”* (Survey respondent)

### 4.3.2 Racism and discrimination

Respondents also report increasing tensions with external communities, in particular a rise in incidents of racism and discrimination. For example, 35% report since the pandemic started racism and discrimination is a lot worse and 22% that is a little worse:



People describe always having had to face racism and discrimination, but there is strong sense that it has been made worse by the pandemic. In particular, people report seeing signs up warning people about Travellers and having to wait longer to be served on shops or refused to be served:

*“Everywhere you go all you hear it’s racist comments about Travellers, it’s like we are not human and don’t warrant being alive...there are posters circulating warning people about Travellers in the area and to report to police if they see them.”* (Survey respondent)

*“The looks that we get everyday are bad, but now it’s even worse it’s not necessarily what’s said to you directly it’s how your treated they tell one person please wait hear to be asked to come forward and I’m told wait their you, made to feel like I shouldn’t be there.”* (Survey respondent)

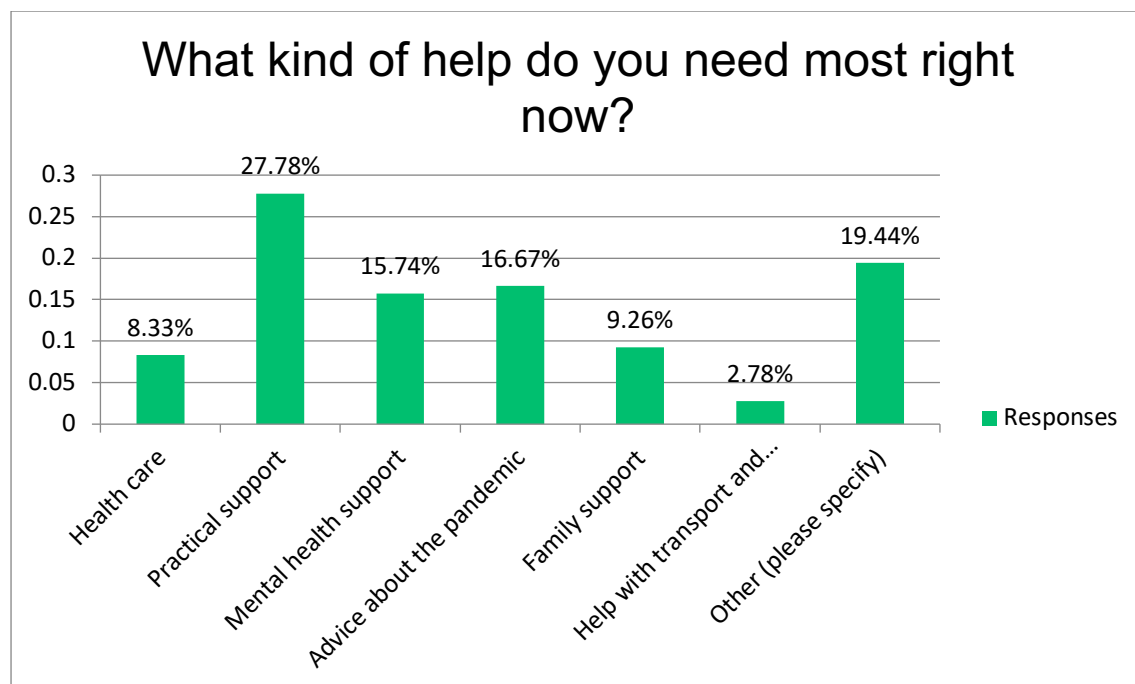
People also report seeing much more hate through social media:

*“There is a lot of prejudice and blame towards the GRT communities on social media, and it’s difficult to read and see all these hateful comments people saying things like Hope all the Gypsies get this Covid and they all die. It hurts to see things like this.”* (Survey respondent)

## 5. Help received

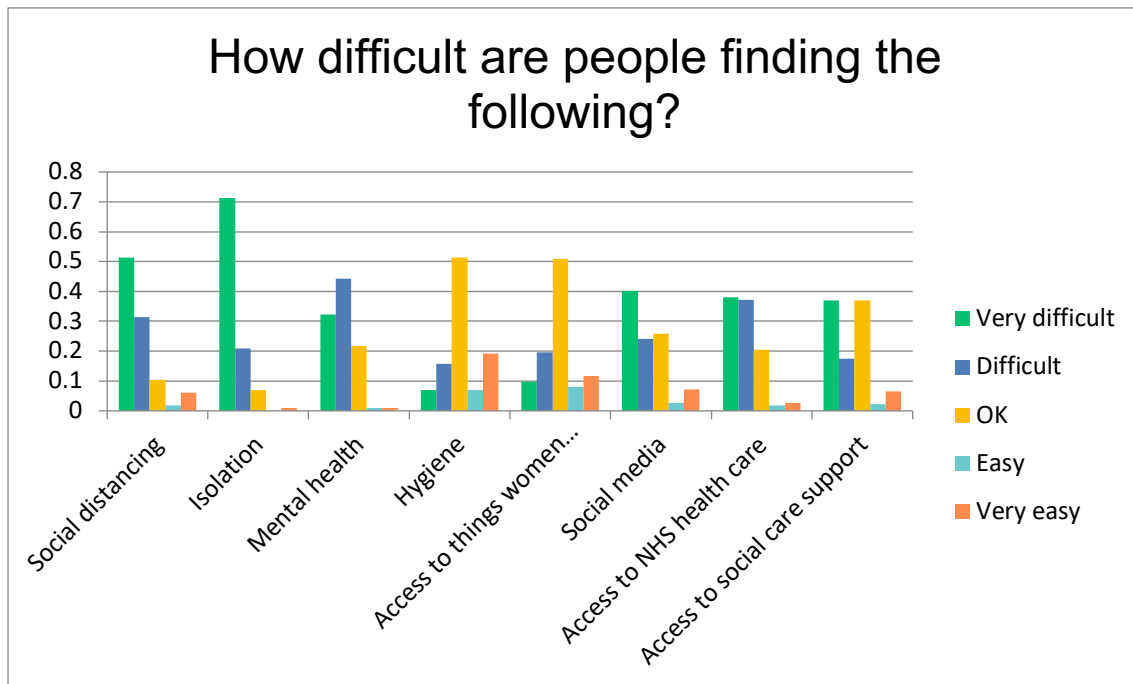
When asked what help people most needed right now from services, nearly one third (28%) said practical support, 17% wanted advice about the pandemic, 16% mental health support. Amongst those citing other forms of help (19%) the following were requested:

- Home schooling of children, especially for parents with low literacy
- Advice on how to get repeat prescriptions
- Help with sanitation, especially where deliveries of water and heating have been disrupted and removal of waste is problematic



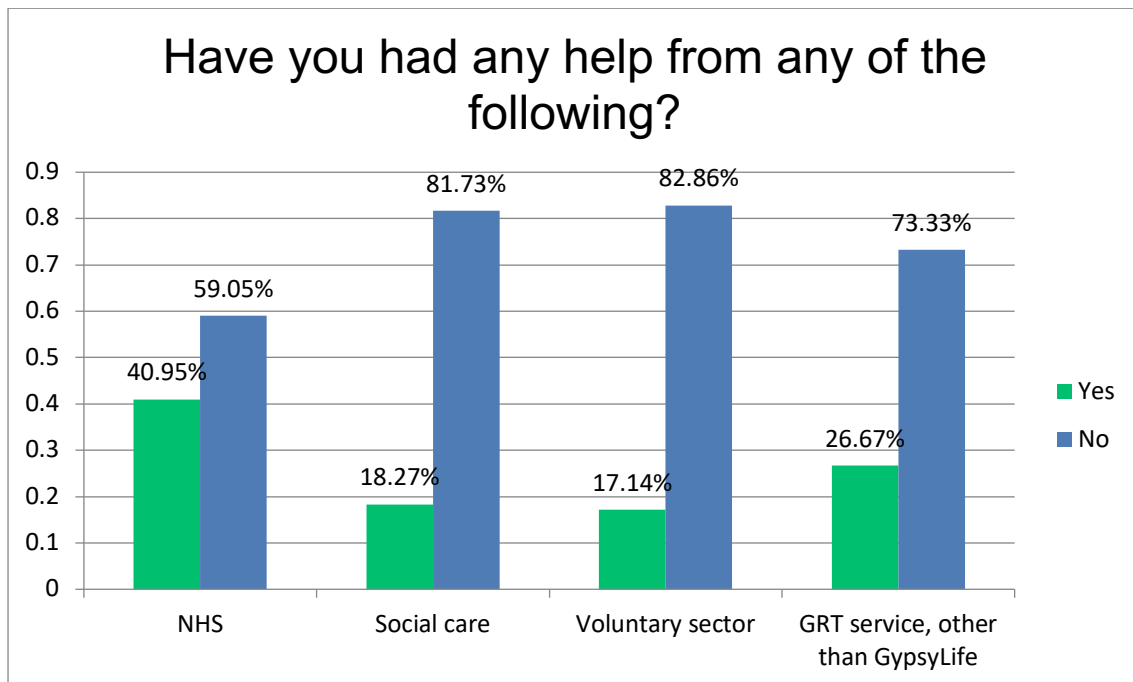
When asked what people found the most difficult to deal with, the majority (71%) said they found isolation very difficult and just over half (51%) found social distancing very hard. 40% found social media very difficult, 32% found dealing with mental health very difficult and 38% found access to health and social care very difficult:





While 50% found dealing with hygiene ok, 10% found access to women’s sanitation very difficult.

When asked about help received from services, fewer than half (41%) had received help from NHS, 18% from social care, 17% from the voluntary sector and 27% from a GRT service other than GypsyLife:

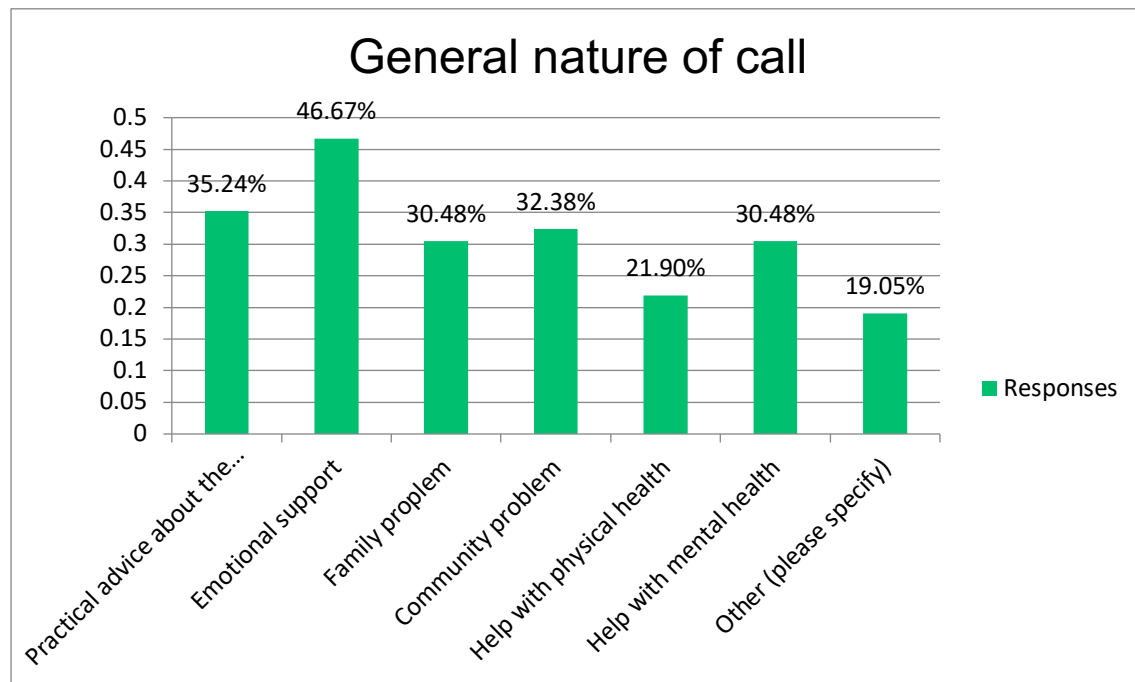


One of the things that people struggled with most was understanding Internet based information, partly due to a lack of digital access but also literacy and understanding the forms and data requested:

*“There is no help from no one and this stupid online thing don’t help because if you’ve got no internet and your reading abilities are not so good then how do you access it, phone the doctor they say no appointments , telephone appointment only, and that’s only after you’ve kicked and screamed still no help.”* (Survey respondent)

## 5.1 Use of the GypsyLife helpline

All respondents were seeking some form of help, advice or guidance in dealing with the pandemic and for most this included more than one reason with emotional support, practical help about the pandemic, help with family problems and help with mental health being the most common:



Most people heard about GypsyLife though friends or family by word of mouth and a few from social media.

All respondents said that they found the call helpful including for emotional support, advice and guidance.

## 6. Summary and recommendations

The Covid-19 pandemic has significant impacts for all communities across the world, but it is clear that some communities and demographic groups have experienced disparities in the impact and outcomes, especially amongst ethnic minority groups. To date however, there has been very little attention paid to the impact of Covid-19 on Gypsy, Roma and Traveller communities.

This report, which is based on the lived experience feedback from 115 GRT community members across England highlights a number of concerning issues:

- Reports about the spread of the virus amongst GRT communities indicates that is high and that is associated with problems maintaining social distancing and the culture and lifestyle of the community including living on closed sites, close family proximity in confined spaces and problems accessing appropriate sanitation and cleaning.
- The reported deaths rates are very high, with the sample of respondents identifying nearly 1,000 GRT community members who have died in the last four months.
- Dealing with grief and bereavement is leaving people feeling very isolated, depressed and worried about their own safety. There is a strong sense that grief is being left unexpressed and that people are struggling to come to terms with the numbers of dead across the community and being unable to grieve in their normal way.
- Many people are experiencing mental health problems associated with the pandemic including isolation, heightened anxiety, poor sleep patterns and increased family and community tensions.
- While there is still resilience in the communities, this is being put under increasing strain and people feel strongly that their culture and lifestyle is permanently under threat.
- The incidents of racism, discrimination and hate speech is on the rise.
- People have struggled to obtain help and advice from statutory services and there is a lack of awareness and knowledge about what can do done to help people and which services they can turn to.

There is still a long way to go before we are free of the pandemic and at this point no one can say if there will be a second wave or what further lock down measures may be needed in the future. But there are some clear needs and important issues that have been identified in this report and the following recommendations are intended to help address these.

## 6.1 Recommendations

### **Recommendation one: Ethnicity data recording**

The lack of official ethnicity data recording that specifically identifies Gypsy, Roma and Traveller communities hinders awareness about the impact of the pandemic on these communities. This needs to be addressed in death certificates by coroners so that the mortality rate for Gypsy, Roma and Travellers can be recognised. Specific data recording for Gypsy, Roma and Travellers should also be adopted across the public sector as part of a more concerted effort to fully identify need and enable an appropriate planning response.

### **Recommendation two: Culturally appropriate advice and support**

Gypsy, Roma and Traveller communities report that they have struggled to access culturally appropriate and sensitive advice and support during the pandemic. There is a need to ensure that the communities can access help, support and advice that they trust, feel is relevant to their needs and understands their culture and lifestyle. This is particularly important for ensuring that instructions and advice about social distancing and how to protect vulnerable community members is understood and adhered to. The health and social care workforce need to be trained in understanding the health needs, risks and vulnerabilities amongst gypsy, Roma and Traveller communities and how to develop culturally appropriate practice to meet these needs. This should be part of the work in vulnerability cells.

### **Recommendation three: Mental health support**

There are very high levels of reported mental health problems, including risks of self-harm and suicide and increased substance use in Gypsy, Roma and Traveller communities. Commissioning for mental health services need to take account of the mental health needs of Gypsy, Roma and Traveller communities and require mental health providers to develop appropriate and accessible services to address these. Suicide prevention plans should specifically consider the risks of self-harm and suicide in these communities and identify ways in which these can be reduced.

### **Recommendation four: Protection for vulnerable people**

As part of the emergency pandemic planning and response programmes and processes, attention should be paid to vulnerable members of Gypsy, Roma and Traveller communities and how best to protect people and keep them safe. This should include working with the communities in the design and production of responses and gaining trust and cooperation from within the community, supported by community led agencies.

### **Recommendation five: Further research based on lived experience**

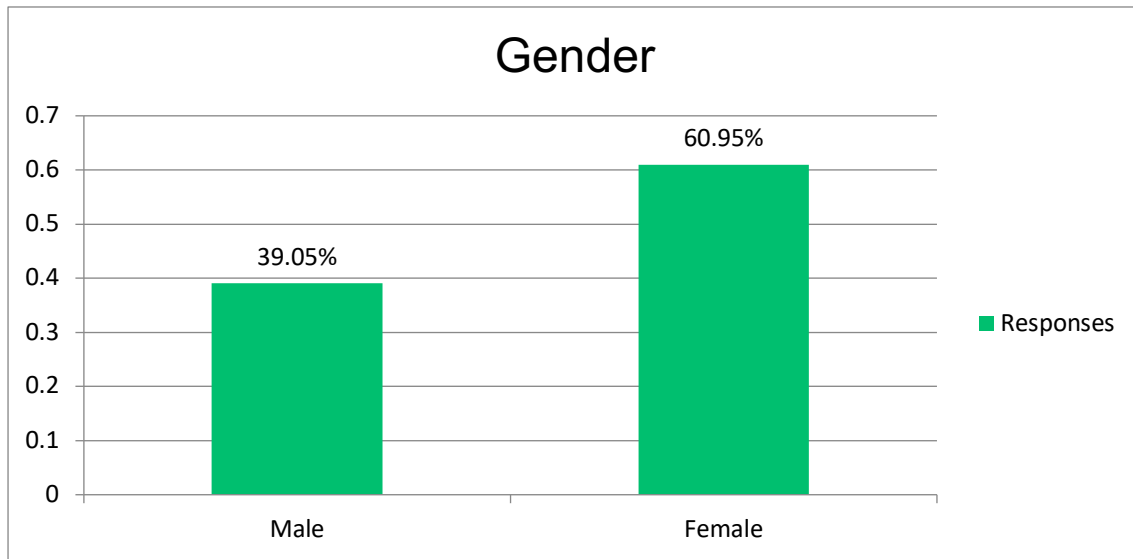
It is essential that the lived experience of community members is able to continue to inform policy and planning and that further work is undertaken to capture the experiences of the community, build trust and dialogue and enable further partnership development in the design and production of needs assessments.

## Appendix A: Demographics of respondents

To date there have been 115 respondents. All interviews were conducted in a completely confidential basis and no individuals, family groups or specific locations are identified in the data.

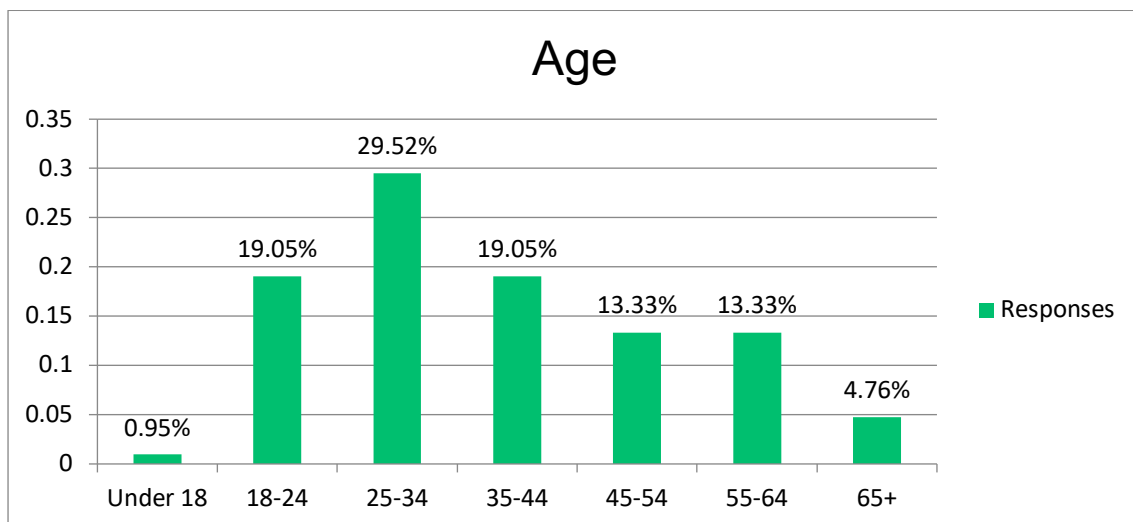
### Gender

The majority of respondents (61%) were female:



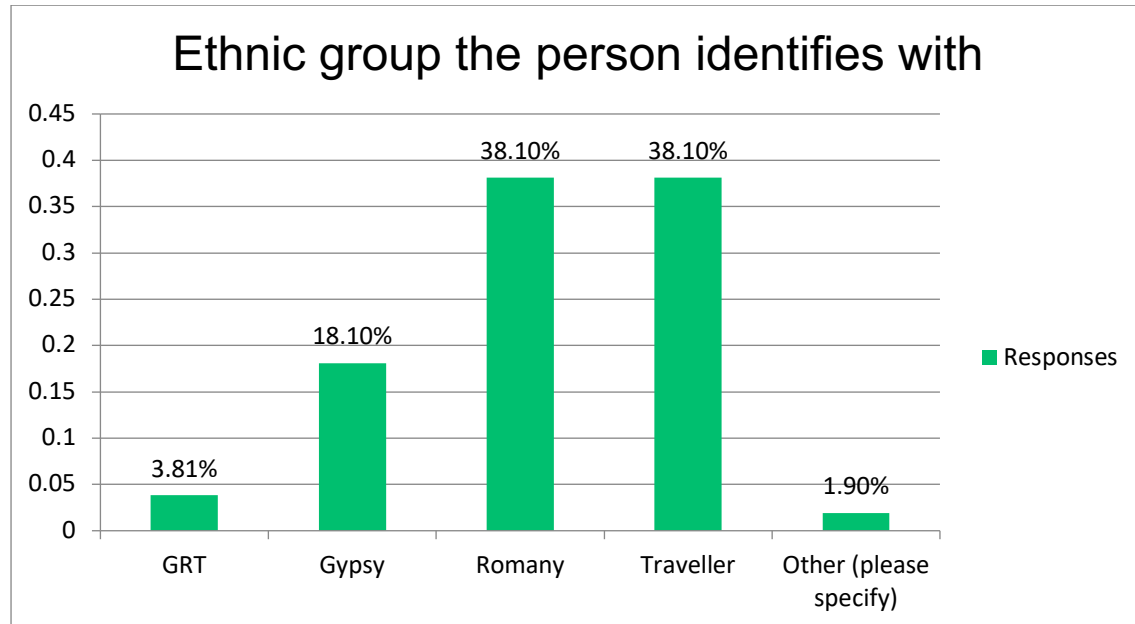
### Age

The majority of respondents were aged between 25 and 44 (48.6%)



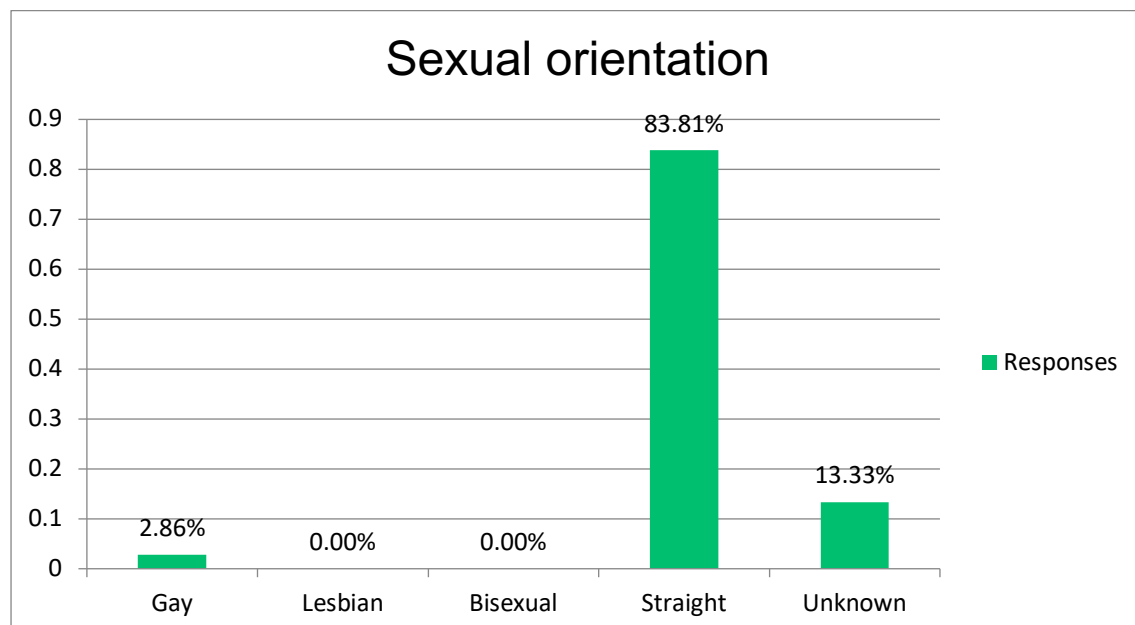
## Ethnicity

Over one third (38%) identified as Romany and a further third (38%) identified as a Traveller:



## Sexual and gender orientation

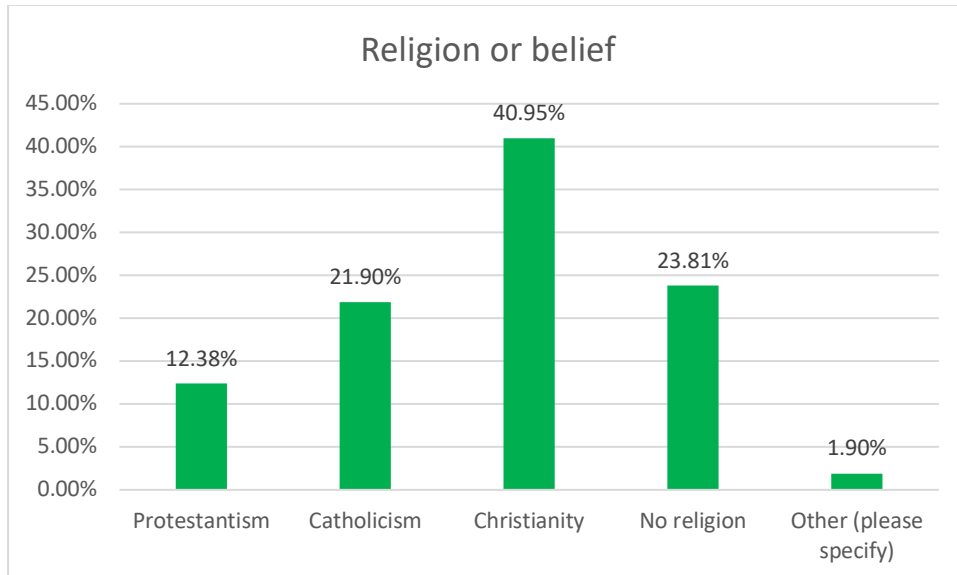
The majority of respondents identified as straight, while 3% identified as Gay and 13% did not specify:



One person did not identify with the sex they were ascribed at birth.

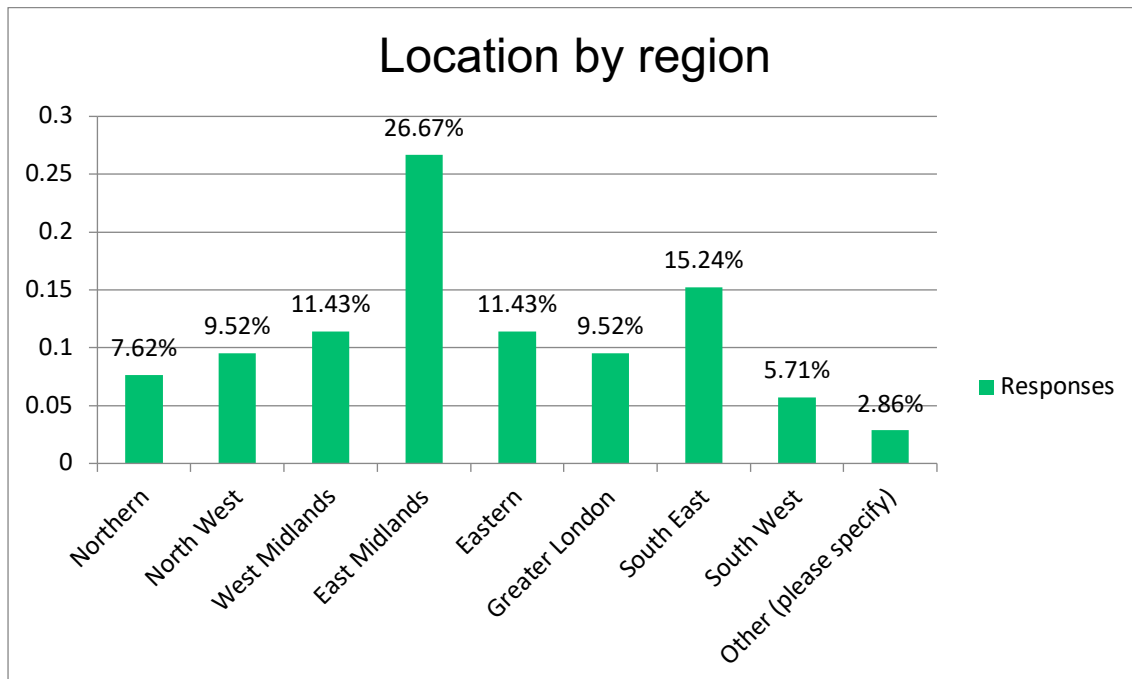
## Religion or belief

Three quarters (75%) identified as Christian and one quarter said that they had no religious belief:



## Location by region

The largest group of respondents were from the East Midlands (27%) followed by South East (15%) and West Midlands (11%):



## Accommodation

More than half of respondents were living on a site with 33% on an official site and 24% on an unofficial one. 27% were living in a house

