

October 2022

Briefing: Health inequalities experienced by Gypsy, Roma and Traveller communities

Friends, Families & Travellers



Briefing: Health Inequalities experienced by Gypsy, Roma and Traveller communities, October 2022

Romany Gypsy, Roma and Irish Traveller communities are known to face some of the starkest inequalities in healthcare access and outcomes amongst the UK population, including when compared with other minority ethnic groups. The reasons for these poor health outcomes are complex, but include the impact of discrimination and stigmatisation, the complicated nature of health systems and the effects of wider social determinants of health.

Key inequalities:

- Romany and Traveller people face life expectancies between ten and 25 years shorter than the general population.²
- Romany and Traveller people experience significantly higher prevalence of long-term illness, health problems or disabilities, which limit daily activities or work.³
- The health of a Romany or Traveller person in their 60s is comparable to an average White British person in their 80s.⁴
- An All Ireland study found that suicide prevalence is six times higher for Irish Traveller women than women in the general population, and seven times higher for Traveller men.⁵
- 60% of Roma Support Group's migrant Roma beneficiaries are reported to have poor physical health, with 43% of Roma beneficiaries of the above reported to suffer from poor mental health.⁶

Key Issues:

There are a number of factors that contribute to poor health outcomes among Gypsy, Roma and Traveller communities. These relate to structural inequalities, social exclusion, and barriers to healthcare services. Key issues include:

- 1. Chronic exclusion across the wider determinants of health.
- 2. Invisibility in mainstream datasets, meaning needs aren't identified within services.
- 3. Lack of trust in services as a result of fear of and experiences of discrimination.



- 4. Wrongful registration refusal in primary care.
- 5. Digital exclusion and lack of accessible information.
- 6. Inequalities in access to healthcare waiting lists for nomadic populations.
- 7. Inequalities in mental health and access to mental healthcare.
- 8. A failure within services to account for premature onset of typically agerelated conditions.

Issue 1: Chronic exclusion across the wider determinants of health

Whilst accessible healthcare is vital, it potentially accounts for as little as 10% of a population's health and wellbeing.⁷ The conditions in which we work and live powerfully influence our health and, whilst issues across the wider determinants remain unaddressed, the effectiveness and benefits of medical intervention are diminished.⁸ Social inequality across a range of areas puts people at far greater risk of poor health, of experiencing poor health earlier in life, and of facing subsequent barriers to healthcare services

Gypsy, Roma and Traveller communities experience chronic exclusion across the wider social determinants, with many people facing multiple inequalities including deprivation, difficulty accessing adequate accommodation, inequalities in education, and barriers to employment. Key figures include:

- 22% of those in employment from a Gypsy or Traveller background work in elementary occupations.⁹
- 60% of Gypsies and Travellers have no formal qualifications.
- Children from Irish Traveller families are over 3 times as likely to be eligible for Free School Meals than White British children.¹¹
- 10,000 Gypsies and Travellers have no place to stop as a result of a chronic national shortage of sites.¹²
- 3,000 families without a permitted stopping place have limited or no access to basic water and sanitation. 13

In addition to the above, Gypsy, Roma and Traveller people may be more likely to be subject to enforcement policies. Hostile environment policies for migrant Roma communities and the criminalisation of trespass within the Police, Crime, Sentencing and Courts Act further exacerbate exclusion and contribute to poor health outcomes.

Cross-government action is urgently needed to tackle the stark inequalities Gypsy, Roma and Traveller communities face across the wider determinants of health, and



the high levels of exclusion and discrimination Gypsy, Roma and Traveller people experience.

Solutions:

- The Department for Levelling Up, Housing and Communities should develop and implement a national cross-government strategy to tackle the inequalities experienced by Gypsy, Roma and Traveller communities, with clear actions across Government to address these stark inequalities.
- Policymakers across Government should routinely adopt a "Health in All Policies" approach to decision-making, with consideration of poor health outcomes faced by Gypsy, Roma and Traveller communities. This should be a key aspect of all equality impact assessments and decision-making, in line with Public Sector Equalities duties.

Issue 2: Invisibility in datasets

As a result of a historic failure to include Gypsy, Roma and Traveller ethnic groups within the NHS Data Dictionary, health and care services currently do not routinely collect disaggregated data on ethnicity for these groups. As such, services may not be identifying the needs of Gypsy, Roma and Traveller patient groups, and may design services that are unwittingly exclusionary.

In addition to this, where services are collecting data, many Gypsy, Roma and Traveller people may be reluctant to disclose ethnicity for fear of experiencing discrimination within services. This further contributes to an underrepresentation of Gypsy, Roma and Traveller patients within data collection, and a failure to identify population needs within local health systems.

Solutions:

- DHSC and NHS England and Improvement should progress the development of a "Unified Information Standard for Protected Characteristics", ensuring that Gypsy, Roma and Traveller ethnicity data is routinely collected within healthcare services.
- DHSC and NHSE&I should work with Gypsy, Roma and Traveller voluntary sector organisations to support with campaigns and communications on raising awareness of the importance of routine data collection on ethnicity to improving service delivery.



Issue 3: Lack of trust in services as a result of fear of and experiences of discrimination

Gypsy, Roma and Traveller people have faced stark historic discrimination, exclusion and persecution, which has significantly damaged trust in government and public services. Over 500,000 Roma and Sinti people were killed during the Holocaust, and this contributes to very real and present fear of engagement with authorities. In addition to this, many Roma women were forcibly sterilised on access to health services across parts of mainland Europe, with the last known case of this as recent as 2007, within the Czech republic.¹⁴ Abhorrent events such as these demonstrate the vital importance that public services undertake significant, concerted action to build trust with Gypsy, Roma and Traveller communities.

In addition to this, the EHRC found that 44% of the British public report having a negative opinion about Gypsies, Roma and Travellers, demonstrating the high levels of social exclusion and discrimination faced by Gypsy, Roma and Traveller people. Concerns around discrimination mean that many Gypsy, Roma and Traveller people may be reluctant to engage with health and care services, and previous poor experiences on accessing services can further damage trust. As such, many Gypsy, Roma and Traveller people may put off attending health services when issues arise, meaning that needs may not be identified until they have reached an acute stage.

Solutions:

- DHSC, NHSE&I and local Integrated Care Systems should routinely commission and build capacity for Gypsy, Roma and Traveller VCSE organisations and assertive outreach services to provide a key bridge between healthcare services and communities.
- Gypsy, Roma and Traveller cultural awareness training should be mandatory within all health and social care services.

Issue 4: Wrongful registration refusal in primary care

Romany and Traveller people in England face longstanding barriers to primary healthcare services. Between 2018 and 2019, Friends, Families and Travellers (FFT) mystery shopped 50 General Practices (GPs) in England and found that, despite no regulatory requirement to provide proof of address or identification in order to



register, nearly half of all GP practices contacted refused registration on this basis.¹⁶ This issue similarly impacts other communities experiencing high levels of inequality, such as migrants in vulnerable circumstances, including migrant Roma people, and people experiencing homelessness.

Within the context of COVID-19, FFT's casework team flagged that a notable shift towards digital-first processes for registration had resulted in additional barriers to care. To gain an updated understanding of access to primary healthcare in this context, FFT mystery shopped 100 GPs in England between March and April 2021.¹⁷ The findings show that:

- 74 GP surgeries broke NHS England guidance and refused to register the mystery shopper because they were unable to provide proof of identity, proof of fixed address, register online or another reason.
- 17 GP surgeries did not answer the phone despite receiving phone calls on three different dates and times from the mystery shopper.
- 2 GP surgeries who otherwise agreed to register the mystery shopper refused to give help with form filling.

For patients experiencing multiple disadvantages, with no address, no identification and low or no literacy leading to digital exclusion, only 6 out of the 100 GP surgeries would have allowed them to register. This means that inequalities in registration for people living nomadically has significantly worsened since FFT's last report in 2019.

In addition to this, many practices will only register patients without a fixed address as temporary patients, despite 2015 guidance stating that practices are free to permanently register patients outside practice boundaries. Temporary registration means that patients won't be invited for a range of preventative care interventions, including cancer screening programmes and immunisations.

Solutions:

Some positive actions have been taken at the central level to address this issue, which includes; the launch of primary care access cards outlining that everyone in England is entitled to register and receive treatment from a GP practice without providing proof of address or ID; multiple provisions of guidance throughout COVID-19 emphasising the rights of patients to register with no fixed address, no ID or proof of immigration status; funding the development of an Inclusion Health Self-Assessment Tool for Primary Care Networks, used by more than 130 PCNs so far.



Ultimately however, these have not been significant enough to change the outcomes of longstanding issues with refused registration, and there is currently no accountability mechanism in place for GP practices which wrongfully refuse registration. The following actions should be taken to address this:

- NHS England and NHS Improvement should develop a national and local accountability framework for GP registrations, in partnership with the Care Quality Commission and the voluntary sector.
- Clinical Commissioning Groups should commission voluntary sector organisations to mystery shop GP practices assessing issues around access within their area.
- Inclusion Health training should be mandatory for practice managers and GP receptionists.
- NHS England and NHS Improvement should update the Patient Registration Standard Operating Principles to clarify the grounds for refusal of nomadic patients who travel outside of practice boundaries, and for nomadic patients' right to register as permanent patients in one practice.

Issue 5: Digital exclusion and accessible information

People within Romany and Traveller communities are more likely to experience digital exclusion as a result barriers to accessing data and devices. Additionally, around 40% of FFT's service users have low or no literacy as a result of educational inequalities, which also impacts digital access. In 2018 FFT interviewed 50 people from Romany and Traveller communities across the UK to find out the extent of digital exclusion and identify barriers for Romany and Traveller people in digital participation. The findings included that:

- Over half of participants said that they did not feel confident using digital technology by themselves.
- Only 38% of Romany and Traveller people (33% if housed) had a household internet connection, compared to 86% of the general population.¹⁹

Whilst the COVID-19 pandemic has required services to adapt to new modes of service delivery, with the provision of remote consultation and online registration, this has significantly exacerbated barriers to healthcare services.



Solutions:

- The Secretary of State for Health and Social Care should make a clear commitment to ensure that patients who choose to access health services through non-digital means should be able to access all NHS healthcare settings.
- NHS England and NHS Improvement should introduce contractual obligations for GP practices to register patients who choose this through non-digital means, unless there are good clinical reasons to the contrary.
- NHS England and NHS Improvement should develop clear guidance and standards for providing accessible communications and appropriate supports to people with low or no literacy in healthcare settings.

Issue 6: Waiting list inequalities for nomadic patients

Friends, Families and Travellers often hears from people living nomadically who have experienced disadvantage on NHS waiting lists which affects their access to, experience of and outcomes from NHS services. Patients often have to start from scratch when moving to a new area, and many have been removed from waiting lists when travelling, which means health needs are often not addressed until needs have reached an acute stage.

The Government's plans to tackle the backlog in elective care waiting lists have been termed "the biggest catchup programme in the NHS's history".²⁰ Without a system to support nomadic patients to retain their place on waiting lists, there is risk that preexisting inequalities will leave nomadic Gypsies, Travellers and Boaters at a significant disadvantage as we enter the recovery stage.

Solutions:

In response to this issue, in March 2021, NHS England and NHS Improvement asked FFT to launch a project exploring ways to address inequalities in healthcare waiting lists for nomadic populations. Discussions have also been had with policy leads at DHSC on the development of an elective care pathway for nomadic patients. In addition to this, the following actions are needed:

 NHS England and NHS Improvement should create a clear information resource for clinicians on responsibilities to nomadic people.



 NHS England and NHS Improvement should work in partnership with voluntary sector organisations and nomadic communities to create and disseminate clear information for nomadic patients on their rights to healthcare, in particular elective care and screenings when travelling and where to go to for support when they are denied.

Issue 7: Mental health inequalities

According to the All-Ireland Traveller Health Study, the suicide rate for members of the Irish Traveller community is six to seven times higher than the general population. Anecdotally, FFT believe the same figure to be true in England. In addition to this, Parry et al found that members of Gypsy and Traveller communities are nearly three times more likely to be anxious than others and just over twice as likely to be depressed, with women twice as likely as men to experience mental health problems. 22

Despite the significant inequalities in relation to suicide within Gypsy and Traveller communities, previous research conducted by Friends, Families and Travellers shows that of 89 local suicide prevention plans representing 110 local areas in England, only 5 mention Gypsy and Traveller communities. Of these 5, only 2 list any action to address the high suicide rate in their local Gypsy and Traveller communities.²³

Despite the fact that Gypsy and Traveller communities are at high risk of poor mental health, members of Gypsy and Traveller communities are often missed out by whole-population approaches to prevent poor mental health. Guidance may be inaccessible for people who have low literacy within Gypsy and Traveller communities; target audiences may be in schools or universities which Gypsies and Travellers may be far more likely to be excluded from or not attending; and prevention activities may take place in workplace settings where Gypsy and Traveller people are less likely to be present in due to self-employment or unemployment. Issues around accessing primary care or lack of awareness of services available, may mean that those seeking help and support may find themselves unable to access it. Friends, Families and Travellers launched guidance for public health and healthcare professionals on how to ensure Gypsy and Traveller communities are included within suicide prevention planning and support²⁴.

Solutions:



- Gypsy and Traveller communities should be listed as a high-risk group in the Cross-Government Suicide Prevention Plan, with actions identified to address this inequality.
- Local Suicide Prevention Plans in areas of the country with a Gypsy or Traveller population should routinely include actions to address this inequality.
- DHSC should ensure Gypsies and Travellers are included in their targeted work with occupational groups at high risk of suicide.
- Research should be undertaken to identify how Gypsy and Traveller community members experiencing bereavement could be better supported.
- Whole-population approaches to prevent poor mental health should be accessible for people with low literacy, who are experiencing digital exclusion and those who are self-employed.

Issue 8: A failure within services to account for premature onset of typically age-related conditions

As a result of stark health inequalities, Gypsy, Roma and Traveller people are more likely to be living with typically age-related conditions earlier in life. This includes the premature onset of conditions such as dementia, falls syndromes and frailty. A University of Manchester study found that the average health of a Romany or Traveller person in their 60s is comparable to that of a White British person in their 80s.²⁵

Despite this, many healthcare services take a primarily age-based rather than needs-based approach to service provision. This means that people experiencing inequalities are excluded from opportunities for prevention and support, and are more likely to experience acute illness and poor health outcomes as a result. As policies increasingly aim to deal with the challenges posed by an ageing population, it's of vital importance that services ensure that groups at the sharp edge of inequality are not further marginalised and excluded.

Solutions:

- Healthcare services should routinely take a needs-based rather than agebased approach to service provision, to ensure the inclusion of groups experiencing premature onset of age-related conditions.
- Healthcare services should routinely offer frailty assessments to Gypsy, Roma and Traveller patients experiencing multiple long-term conditions.



About us

Friends, Families and Travellers is a leading national charity that works to end racism and discrimination against Gypsy, Roma and Traveller people and to protect the right to pursue a nomadic way of life.

<u>www.gypsy-traveller.org</u> | Telephone +44 (0)1273 234 777 | Email <u>fft@gypsy-traveller.org</u> Twitter <u>@GypsyTravellers</u> | Facebook <u>@FriendsFamiliesandTravellers</u>

Appendix 1: Legal duties to reduce inequalities

It is important to note that health and care services have clear legal, as well as moral, reasons to tackle health inequalities in their everyday work. Staff across services should all be aware of their legal duties to improve access to services and to reduce inequalities. This includes:

The Equality Act 2010 prohibits unlawful discrimination in the provision of healthcare services on the basis of "protected characteristics", and imparts a duty on services to advance equality of opportunity. This includes both direct discrimination where a person is treated worse than another person because they have a protected characteristic or indirect discrimination when there is a policy that applies in the same way for everybody but disadvantages a group of people who share a protected characteristic.

The Health and Social Care Act 2012 also sets out specific legal duties on health inequalities which require NHS England to "(a) reduce inequalities between patients with respect to their ability to access health services; and (b) reduce inequalities between patients with respect to the outcomes achieved for them by the provision of health services".

<u>Public Sector Equality Duty</u> imparts a responsibility to remove or minimise the disadvantages suffered by people due to their protected characteristics; take steps to meet the needs of people from protected groups where these are different from the needs of other people; and to encourage people from protected groups to participate in public life.

¹ Parry et al (2007) 'Health status of Gypsies and Travellers in England'. J Epidemiol Community Health. 2007 Mar; 61(3): 198–204.

² https://www.equalityhumanrights.com/en/gypsies-and-travellers-simple-solutions-living-together

³ Ibid.

⁴ https://www.manchester.ac.uk/discover/news/study-reveals-huge-ethnic-minority-health-inequalities/

⁵ https://www.ucd.ie/t4cms/AITHS SUMMARY.pdf

⁶ Ihid



⁷ https://www.health.org.uk/newsletter-feature/addressing-social-determinants-of-health-through-the-nhs

⁸ http://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review/fair-society-healthy-lives-full-report-pdf.pdf

⁹ Office for National Statistics (2011) 'What does the 2011 Census tell us about the characteristics of Gypsy or Irish Travellers in England and Wales?': <a href="https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/datasets/2011censusanalysiswhatdoesthe2011censustellusaboutthecharacteristicsofgypsyoririshtravellersinenglandandwales

10 Ibid.

 11 Dept. of Education (2018) 'Latest percentage eligible for Free School Meals by ethnicity': $\underline{\text{https://www.whatdotheyknow.com/request/latest}} \ \ \text{percentage} \ \ \text{eligible} \ \ \text{for} \ \ \text{f}$

¹² MHCLG (2019) 'Traveller caravan count: January 2019': https://www.gov.uk/government/statistics/traveller-caravan-count-january-2019

13 Ibid

- $^{14}\,\text{https://www.euronews.com/2021/08/02/the-shameful-story-of-roma-women-s-forced-sterilisation-in-central-europe}$
- ¹⁵ https://www.equalityhumanrights.com/sites/default/files/national-barometer-of-prejudice-and-discrimination-in-britain.pdf
- ¹⁶ https://www.gypsy-traveller.org/resource/no-room-at-the-inn-how-easy-is-it-for-nomadic-gypsies-and-travellers-to-access-primary-care/
- ¹⁷ https://www.gypsy-traveller.org/news/locked-out-74-of-gps-refused-registration-to-nomadic-patients-during-covid-19-pandemic/

¹⁸ https://www.nhs.uk/nhs-services/gps/registering-with-a-gp-outside-your-area/

¹⁹ https://www.gypsy-traveller.org/wp-content/uploads/2018/09/Digital-Inclusion-in-Gypsy-and-Traveller-communities-FINAL-1.pdf

²⁰ https://www.radionewshub.com/articles/news-updates/8395

21 https://www.gov.ie/en/publication/b9c48a-all-ireland-traveller-health-study/

- ²² Parry et al (2007) 'Health status of Gypsies and Travellers in England'. J Epidemiol Community Health. 2007 Mar; 61(3): 198–204.
- ²³ https://www.gypsy-traveller.org/wp-content/uploads/2020/10/Suicide-Prevention-Report-FINAL.pdf
- $^{24} \, \underline{\text{https://www.gypsy-traveller.org/wp-content/uploads/2022/09/Suicide-Inequalities-agencies-report.pdf}$
- 25 https://www.manchester.ac.uk/discover/news/study-reveals-huge-ethnic-minority-health-inequalities/