



## About the Traveller Movement

The Traveller Movement (TM) is a leading national charity, working in partnership with Gypsies, Roma and Travellers, service providers and policy makers developing forward-looking strategies to challenge discrimination and promote increased race equality, social inclusion and community cohesion.

## Inclusion of Gypsy, Roma, and Traveller ethnicities in the NHS Data Dictionary

December 2022

### Introduction

In 2010, The Equality Act brought together 116 distinct pieces of legislation together under a single Act. The Act provides a clear legal framework that protects the rights of all individuals from unfair and discriminatory treatment, and promotes equality of opportunity for all.

The Act specifically recognises Gypsies, Roma, and Travellers as distinct ethnic minorities, and builds on previous race relations legislation to establish a clear and unambiguous legal duty for public bodies to monitor and tackle discrimination in the provision of public services.

Gypsy, Roma, and Traveller are 3 distinct ethnic groups, but are frequently grouped together owing to a strong history and cultural tradition of nomadism. It is important whilst the three ethnicities are grouped due to a shared history of nomadism, contemporary nomadism is not a requirement in order for individuals to be considered members of these ethnic groups. Gypsy, Roma, and Traveller people retain their ethnicity regardless of the type of accommodation in which they live, as a recent Court of Appeal ruling has confirmed.<sup>1</sup>

The 2011 census was the first to include a Gypsy/Irish Traveller category, resulting in a recorded population of 57,680. The number of individuals disclosing Gypsy/Irish Traveller ethnicity in the 2021 census rose significantly to 67,768 – an increase of 17.5%.

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<sup>1</sup> <https://www.gypsy-traveller.org/news/planning-definition-of-traveller-ruled-discriminatory/>



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The recorded Gypsy, Roma, and Traveller population was further increased between the 2011 and 2021 censuses with the inclusion, for the first time, of Roma as a distinct category in the 2021 census; leading to a recorded Roma population of 100,981.

The combined Gypsy, Roma, and Traveller population of 168,749 is likely to be a significant underestimate, as many members of Gypsy, Roma, and Traveller communities are distrustful of public bodies and are reluctant to participate in the census. Research from the University of Salford has estimated the true size of the population may be as high as 500,000.<sup>2</sup>

Despite legal recognition of Gypsies, Roma, and Travellers as ethnic groups and evidence demonstrating the size of the Gypsy, Roma, and Traveller population in the UK, the groups are not included in the NHS's data dictionary. This omission severely impacts the ability of the NHS, and the Department for Health and Social Care (DHSC), to accurately assess the health needs of Gypsy, Roma, and Traveller people, and to implement appropriate policy interventions in response to identified need. In addition, the inability of Gypsy, Roma, and Traveller people to be able to disclose their own ethnicity in a healthcare setting may negatively impact willingness to engage with and access healthcare.

Despite the omission of Gypsy, Roma, and Traveller ethnicities from the NHS data dictionary, the UK Government and Parliamentary Select Committees have independently acknowledged that Gypsy, Roma, and Traveller people experience disproportionately poor outcomes in health and social care.

A national information standards notice (ISN), issued by the DHSC through NHS Digital would greatly enhance the ability of health services to meet the health needs of Gypsy, Roma, and Traveller communities.

### **Available data on health outcomes**

The exclusion of Gypsy, Roma, and Traveller ethnicities from the NHS data model and dictionary is, by definition, a significant barrier to the accurate assessment of health outcomes both in terms of individual experiences as well as wider societal patterns and trends.

Data from the 2011 census indicates that Gypsy and Irish Traveller had the lowest levels of self-reported 'good' or 'very good' general health of any ethnic group at 70%, compared with a national average of 81%. Conversely, 14% of Gypsies and Travellers considered

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<sup>2</sup> [https://hub.salford.ac.uk/care-shusu/wp-content/uploads/sites/125/2020/06/Migrant\\_Roma\\_in\\_the\\_UK\\_final\\_report\\_October\\_2013.pdf](https://hub.salford.ac.uk/care-shusu/wp-content/uploads/sites/125/2020/06/Migrant_Roma_in_the_UK_final_report_October_2013.pdf)

themselves to have 'bad' or 'very bad' general health, more than twice the rate of the overall population.<sup>3</sup>

Further analysis of 2011 Census data by the Centre on the Dynamics of Ethnicity (CODE) found that that Gypsies and Travellers had twice the rate of long-term limiting illness than the White British population, and are the group that are most likely to be ill in every single age bracket.<sup>4</sup>

The Equality and Human Rights Commission have estimated that Gypsy and Traveller life expectancy is 10 years lower than the national average<sup>5</sup>, whilst the House of Lords Public Services Committee has stated it may be as much as 25 years lower than the national average, a figure which they described "stark and shocking", whilst also noting that "it is not clear what the Government is doing to address [these] inequalities".<sup>6</sup>

Gypsy, Roma, and Traveller communities experience mental ill health at significantly higher rates than the average population and research from the Republic of Ireland – a country with a comparable socioeconomic position and similar demographics to the UK – estimates that the suicide rate amongst Irish Travellers is as high as 6 times that of the non-Traveller population.<sup>7</sup>

The 2010 Marmot review states unequivocally that "health inequalities result from social inequalities"<sup>8</sup> and, across a wide range of social indicators, Gypsy, Roma and Traveller experience disproportionality and inequalities that are associated with poor health outcomes.

Gypsy, Roma, and Traveller people are less likely to own their home, and substantially more likely to be living in rented social housing (42%) or privately rented accommodation (24%) than the wider population for whom the figure is 18%. Over half of Gypsy, Roma, and Traveller people are recorded as economically inactive and, for those who are employed, they are represented in routine and semi-routine occupations to a higher extent than any other ethnic group. Those working in routine and semi-routine occupations are regularly,

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<sup>3</sup><https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/whatdoesthe2011censusstellusaboutthecharacteristicsofgypsyoririshtravellersinenglandandwales/2014-01-21#health-and-related-characteristics>

<sup>4</sup>

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/490846/NIHB\\_-\\_Gypsy\\_and\\_Traveller\\_health\\_accs.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/490846/NIHB_-_Gypsy_and_Traveller_health_accs.pdf)

<sup>5</sup> <https://www.equalityhumanrights.com/en/gypsies-and-travellers-simple-solutions-living-together#:~:text=Life%20expectancy%20for%20Gypsy%20and,the%20death%20of%20a%20child.>

<sup>6</sup> <https://www.parliament.uk/business/lords/media-centre/house-of-lords-media-notice/2022/may-2022/stark-and-shocking-inequality-faced-by-gypsies-roma-and-travellers--lords-committee/>

<sup>7</sup> <https://wp-main.travellermovement.org.uk/wp-content/uploads/2021/09/Mental-Health-and-Suicide-among-GRT-communities-in-England-Briefing-2019.pdf>

<sup>8</sup> <https://www.instituteoftheequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review>

but not exclusively exposed to precarity via zero-hours contracts, lower wages, and unfavorable terms and conditions.<sup>9</sup>

### **Best Practice ethnic monitoring**

DHSC's failure to ensure Gypsy, Roma, and Traveller ethnicities are included in the NHS data model and dictionary is contrary to the Government's best practice and internal guidance as evidenced across a range of Government publications and strategies.

Improving data for Gypsy, Roma, and Traveller populations is a recommendation of the Inclusive Data Taskforce<sup>10</sup>. A quality improvement plan published by the Government's Race Disparity Unit stated that it would

*"[work] with departments to maintain a harmonised approach to collecting data about Gypsy, Roma and Traveller people using the classifications proposed for the 2021 Census"<sup>11</sup>*

Inclusive Britain, the Government's official response to the Commission on Race and Ethnic Disparities, acknowledged in broad terms the importance of data quality with regard to ethnic disparities.<sup>12</sup>

As the previous section denotes, the evidence base of smaller-scale research sufficiently demonstrates the significant health disparities experienced by Gypsy, Roma, and Traveller communities. Enhanced collection of ethnicity data by the Government would allow the findings of smaller studies to be generalised across broader population; providing policymakers with the means to make more effective, and targeted, evidence-based policy interventions.

The collection of ethnicity data which, by design, allows for individuals to self-identify their own ethnicity additionally has a positive effect on the inclusion of marginalised, alienated, and disenfranchised groups of people, and allows policymakers improved access to the lived experience of different cohorts of people.

### **Case Study: The NHS GP Patient Survey**

The annual GP Patient Survey is an independent survey which allows patients to provide information on their experiences of their GP and to access sound and credible information

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<sup>9</sup> <https://www.ethnicity-facts-figures.service.gov.uk/summaries/gypsy-roma-irish-traveller#home-ownership-data>

<sup>10</sup> <https://uksa.statisticsauthority.gov.uk/publication/inclusive-data-taskforce-recommendations-report-leaving-no-one-behind-how-can-we-be-more-inclusive-in-our-data/>

<sup>11</sup> <https://www.gov.uk/government/publications/quality-improvement-plan-government-ethnicity-data/quality-improvement-plan-government-ethnicity-data>

<sup>12</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061421/Inclusive-Britain-government-response-to-the-Commission-on-Race-and-Ethnic-Disparities.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061421/Inclusive-Britain-government-response-to-the-Commission-on-Race-and-Ethnic-Disparities.pdf)

on GP practices across the UK, as well as providing GP practices with data which can be used to improve patient experience.

The survey sample for the GP Patient Survey is drawn from NHS Digital's Personal Demographics Service (PDS), which helps healthcare professionals to identify patients and match them with their health records<sup>13</sup>. The PDS does not include information on ethnic group<sup>14</sup>, but does allow for individuals to state their own ethnicity for the purposes of the survey itself, though this does not then result in their ethnicity information being linked to the PDS.

In the most recent GP Patient Survey Gypsy, Roma, and Traveller respondents comprised of 0.07 of all responses, which is a significantly smaller percentage relative to the Gypsy, Roma, and Traveller population in the UK. Nonetheless, the DHSC have acknowledged that:

*“Although the latest survey data has relatively small numbers of Gypsy, Roma and Traveller respondents, the findings are still valuable at a national level, and they demonstrate the different experience of those communities.”<sup>15</sup>*

The GP Patient Survey is one of innumerable examples in which inclusion of Gypsy, Roma, and Traveller ethnicities in the NHS data model and dictionary would improve outcomes; by increasing the value of available findings at national levels; giving GPs a much clearer ideas of the communities they serve; and by increasing inclusion for and participation of people from Gypsy, Roma, and Traveller backgrounds in healthcare.

### **Government position**

The Government's current position on the inclusion of Gypsy, Roma, and Traveller ethnicities within the NHS data model and dictionary is unclear. In response to two parliamentary questions submitted on 4<sup>th</sup> July 2022 and 6<sup>th</sup> December 2022 which make specific reference to Gypsy, Roma, and Traveller ethnicities, DHSC provided a stock response:

*“The NHS Data Model and Dictionary reflects the latest approved Information Standard for the data submission of ethnicity categories in the National Health Service. This is derived from the Office for National Statistics' categories in 2001, which do not currently include Gypsy/Romany Gypsy, Roma, and Irish Traveller groupings.”<sup>16</sup>*

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<sup>13</sup> <https://digital.nhs.uk/services/demographics>

<sup>14</sup> <https://questions-statements.parliament.uk/written-questions/detail/2022-12-15/111745>

<sup>15</sup> <https://questions-statements.parliament.uk/written-questions/detail/2022-07-04/29966>

<sup>16</sup> <https://questions-statements.parliament.uk/written-questions/detail/2022-12-06/104474>

In response to a separate question submitted on 15<sup>th</sup> July 2022, which made reference to improving ethnic coding but did not explicitly reference Gypsy, Roma, or Traveller ethnicities, DHSC response stated:

*“The National Health Service Data Model and Dictionary reflects the latest approved Information Standard for the data submission of ethnicity categories in the NHS, using the Office for National Statistics’ 2001 categories. The content of these categories is updated when the Information Standards are amended.*

*The NHS Data Model and Dictionary Service has contributed to a project to update these Standards. The project is currently finalising a report supporting the development of a ‘Unified Information Standard for Protected Characteristics’. This project is considering the update to the 2001 ethnicity categories and other protected characteristics described in the Equality Act 2010.”<sup>17</sup>*

It is not clear why the DHSC have made reference to ‘Unified Information Standard for Protected Characteristics’ in response to questions on ethnicity more broadly, but not in response to questions on Gypsy, Roma, and Traveller groups specifically; and it is not clear if Gypsy, Roma, and Traveller ethnicities will be specifically included within this revised guidance.

At the 2022 Traveller Movement annual conference, a DHSC policy advisor stated that the DHSC:

*“...are aware of gaps in our [DHSC’s] evidence base...don’t have formal data on ethnicity collected either at Coroners or the NHS...we [DHSC] as a team accept that it is not doing enough”*

## **Conclusion**

Gypsy, Roma, and Traveller communities experience high levels of exclusion, and exceptionally poor health outcomes in the NHS, many of which appear to be entrenched and largely multi-generational. There are myriad social and economic factors influencing these outcomes but one significant factor is the failure to include these groups within data collection, severely hampering frontline healthcare practitioners and policymakers alike.

The Government have acknowledged the desirability and benefit of improving data for minority populations in healthcare; and for Gypsy, Roma, and Traveller populations across a range of different policy areas. If these are serious commitments, and they are serious about their obligations the Equality Act 2010, the Health and Social Care Act 2012, and the

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<sup>17</sup> <https://questions-statements.parliament.uk/written-questions/detail/2022-07-15/37618>

NHS Constitution, then they must commit to amending the NHS data model and dictionary by the end of 2023.