

NHS Data Dictionary Update for Gypsies, Roma and Travellers to 2021 census

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Cultural Context/Background

- Romany Gypsy, Roma and Traveller people make up 0.5% or 1 in 200 of the population:
 - The 2021 UK Census, 172,465 people from Gypsy, Roma and Traveller communities disclosed their ethnicity¹, whereas in the 2011 UK Census only 63,000 people identified themselves as part of these groups.² However, census engagement is negatively impacted by a trust gap between Gypsy, Roma and Traveller communities and state institutions/public services. The census is likely to be an undercount, with the population of Gypsy, Roma and Traveller communities potentially numbering 500,000.
- The term 'Gypsy, Roma and Traveller' is an umbrella term that encompasses various communities, including³:
 - Romany Gypsies
 - Scottish Gypsy Travellers
 - Welsh Gypsies
 - Irish Travellers
 - New Travellers
 - Liveaboard Boaters

¹ FFT, 2023, *Guidance: Tackling Maternal Health Inequalities in Gypsy, Roma and Traveller Communities*, p.10-11, <https://www.gypsy-traveller.org/wp-content/uploads/2023/07/Extended-Maternal-Health-Inequalities-Guidance.pdf>

² House of Commons, 2019, *Gypsies and Travellers*, p. 11, <https://researchbriefings.files.parliament.uk/documents/CBP-8083/CBP-8083.pdf>

³ GOV UK, 2022, *Gypsy Roma and Irish Traveller ethnicity summary*, <https://www.ethnicity-facts-figures.service.gov.uk/summaries/gypsy-roma-irish-traveller/#the-gypsy-roma-traveller-group>



- Showmen
- Roma
- These categories can be found across the 2021 Census and Systematised Nomenclature of Medicine Clinical Terms (SNOMED CT), often with inconsistent degrees of aggregation/disaggregation (e.g., the use of 'Gypsy/Irish Traveller' in declaration forms).
- Traditionally, people from Gypsy and Traveller communities have lived nomadic lives in the UK. However, members of these communities have increasingly moved into bricks and mortar housing (75% recorded in England and Wales in the 2021 Census).

Health outcomes

- Gypsy, Roma and Traveller people disproportionately suffer considerably poorer health than that of the general population and are considered part of an inclusion health group.
- There is a 7.1-year life expectancy difference at birth between Irish Traveller/Romany Gypsy women and the general female population and a 10.3-year difference for men⁴, with health expectancy deteriorating rapidly after the age 50.⁵
- While 18% of the general population is affected by a long-term health condition, this exponentially rises to 42% Gypsy, Roma and Traveller communities⁶ suffering of multi-morbidities.⁷ The average health of a Gypsy, Roma or Traveller person in their 60s is equivalent to that of a white British person in their 80s. This often leads to a failure of services to account for premature onset of typically age-related conditions.⁸
- Gypsy, Roma and Traveller communities face high rates of both infant and maternal mortality, with 1 in 5 women experiencing the death of a child compared to 1 in 100 in the general population.⁹

⁴ European Union Agency for Fundamental Rights, 2020, *Roma and Travellers in Six Countries*, https://fra.europa.eu/sites/default/files/fra_uploads/fra-2020-roma-travellers-six-countries_en.pdf

⁵ Aspinall, Peter J., 2014, p. 35, *Hidden Needs: Identifying Key Vulnerable Groups in Data Collection: Vulnerable Migrants, Gypsies and Travellers, Homeless People, and Sex Workers*, Centre for Health Services, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/287805/vulnerable_groups_data_collections.pdf

⁶ *Patience experience of primary care: GP services*, 20 March 2019, <https://www.ethnicity-facts-figures.service.gov.uk/health/patient-experience/patient-experience-of-primary-care-gp-services/latest/>

⁷ Oral evidence provided by Michelle Gavin to the Women and Equalities Committee in 2018, <https://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/women-and-equalities-committee/tackling-inequalities-faced-by-the-gypsy-roma-and-traveller-communities/oral/81634.html>

⁸ FFT, 2022, *Briefing: Health inequalities experienced by Gypsy, Roma and Traveller communities*, p. 10, https://www.gypsy-traveller.org/wp-content/uploads/2022/11/Briefing_Health-inequalities-experienced-by-Gypsies-and-Travellers-in-England.pdf

⁹ FFT, 2023, *Tackling Maternal Health Inequalities in Gypsy, Roma and Traveller Communities*, p.15-16 <https://www.gypsy-traveller.org/wp-content/uploads/2023/07/Extended-Maternal-Health-Inequalities-Guidance.pdf>



- Gypsy, Roma and Traveller groups face excess burden of measles and whooping cough infections due to low rates of vaccinations¹⁰ with recurring clustered outbreaks of measles. Identifying under-vaccinated communities is not possible due to the lack of data in the NHS Data Dictionary.¹¹

Organisations involved in and recommendations for the NHS DD update

Over the last 10 years, various organisations, academics and parliamentary committees have highlighted the urgent need to update the NHS Data Dictionary to ensure efficient national data capture, which has included (but by no means exclusively):

- **2001:** Friends, Families and Travellers (FFT) issued initial NHS guidance to improve the protocols for recording ethnicity in a Data Set Change Notice.
- **2014:** Inclusion Health Board report argued that the adoption of the 2011 Census ethnic classification across NHS organisations would have “a transformative effect on the capture of Gypsies/Irish Travellers in routine data collection”.¹²
- **2014:** Traveller Movement highlighted that such an update would comply with the legal duties on health inequalities laid out in the Health and Social Care Act 2012.¹³
- **2014:** [Aspinall \(2014\)](#) (cited by Unwin et al) also noted the significant inconsistencies in the cultural classifications being used across a range of NHS services in England and across the UK, which remain in existence. For instance, the General Practitioner Extraction Service (GPES) data set has 18 ethnic categories (based on the 2011 Census) whereas the Hospital Episode Statistics (HES) data set only contains 16 ethnic categories. HES contains no Gypsy, Roma, or Traveller categories and GPES has only a ‘Traveller’ category. Consequently, data on Roma is absent in both GPES and HES, and data on Gypsies and Travellers are absent in HES and minimal in GPES (ONS, 2024).
- **2015:** FFT report on ‘Inclusion of Gypsy Traveller Health Needs in Joint Strategic Needs Assessments’ made the recommendation to update the Ethnic Monitoring services in line with 2011 Census.

¹⁰ Aspinall, Peter J., 2014, p. 35-36, *Hidden Needs: Identifying Key Vulnerable Groups in Data Collection: Vulnerable Migrants, Gypsies and Travellers, Homeless People, and Sex Workers*, Centre for Health Services, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/287805/vulnerable_groups_data_collections.pdf

¹¹ Bell, S., et al, 2020, *Responding to Measles outbreaks in underserved Roma and Romanian Populations in England*, <https://pmc.ncbi.nlm.nih.gov/articles/PMC7374803/#sec4>

¹² Aspinall, Peter J., 2014, p. 11, *Hidden Needs: Identifying Key Vulnerable Groups in Data Collection: Vulnerable Migrants, Gypsies and Travellers, Homeless People, and Sex Workers*, Centre for Health Services, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/287805/vulnerable_groups_data_collections.pdf

¹³ Traveller Movement, 2014, *Note on Inclusion of Gypsies and Irish Travellers in the NHS data dictionary*, p.3, <https://wp-main.travellermovement.org.uk/wp-content/uploads/2021/09/Inclusion-of-Gypsies-and-Irish-Travellers-in-the-NHS-Data-Dictionary-2014-Briefing.pdf>



- **2018 onwards:** Numerous [Parliamentary Questions and correspondence](#) from the All Party Parliamentary Group on Gypsies, Travellers and Roma.
- **2019:** House of Commons Women and Equalities Committee reported consistent failure by local and national policy to address health inequalities experienced by Gypsy, Roma and Traveller communities.¹⁴ The Women and Equalities Committee also urged the Race Disparity Unit to review all the Government and public datasets that did not use the 2011 Census ethnicity classifications and require their use before the end of 2019.
- **2022:** the UK Statistics Authority Inclusive Data Taskforce¹⁵ asserted the necessity of inclusive data with specific mention of Gypsies Roma and Travellers.

Current and past consequences

- The inability to record Gypsy, Roma and Traveller ethnicities means local authorities are forced to establish local ethnic codes to effectively monitor need and community experiences. However, an overwhelming majority of Integrated Care Systems—formerly Clinical Commissioning Groups—have stated that they do not include these groups because of their absence in the NHS Data Dictionary¹⁶, since it sets the mandatory standards for the collection of data across NHS bodies.
- This leads to lack of commissioning, as stated in the 2019 WEC report, “on a big national level, even on a county council level or on an NHS level, you cannot commission for what you do not know. You cannot go and do cultural competency in a hospital that does not even recognise that it might have a Gypsy/Traveller community that it serves.”
- Without the appropriate data, commissioning and improvement strategies are hindered. An Equality and Human Rights Commission article on maternal mortality highlighted the importance of updating the NHS Data Dictionary to effectively implement appropriate health strategies.
- COVID-19 further highlighted the discrepancies in data collection for Gypsy, Roma and Traveller communities. The lack of appropriate ethnicity monitoring in England has led to a significant data error whereby NHS data shows no COVID-19 deaths for people from Gypsy, Roma and/or Traveller communities. This is not the case in Scotland where the NHS Data Dictionary aligns with a more recent census.

¹⁴ FFT, 2023, *Tackling Maternal Health Inequalities in Gypsy, Roma and Traveller Communities*, p.15
<https://www.gypsy-traveller.org/wp-content/uploads/2023/07/Extended-Maternal-Health-Inequalities-Guidance.pdf>

¹⁵ UKSA, 2022, *Inclusive Data Taskforce recommendations report: Leaving no one behind – How can we be more inclusive in our data? – UK Statistics Authority*

¹⁶ Inclusion Health Board, 2016, *Impact of insecure accommodation and the living environment on Gypsies' and Travellers' health*, p. 30, <https://wp-main.travellermovement.org.uk/wp-content/uploads/2021/09/Impact-of-Insecure-Accommodation-on-GRT-Health-2016.pdf>



How an immediate change would affect Gypsy, Traveller and Roma communities

- Public Health Scotland asserted that the introduction of a 'Gypsy/Traveller' code was essential in conducting studies on vaccination rates and identifying reasons for low uptake during the COVID-19 pandemic. They acknowledged that this data was crucial in formulating targeted actions to enhance vaccine confidence, particularly by refining their communication strategies.¹⁷
- Prevention as part of the 10-year plan, including reducing A&E attendance, would be enabled by identifying and helping populations who traditionally present late and acute with preventable health conditions.
- Taking a whole system approach by aligning the NHS Data Dictionary to the 2021 Census would not only enable a whole system approach within the NHS but would also make sure that health data is collected in line with ONS and various other governmental institutions that have adopted the 2021 Census.
- This would also ensure the 10-year plan and the digital aspect is truly representative of the whole population and reduce health inequalities at national and local levels, when NHS England sets out equality objectives for 2024/25 and 2025/26.
- FFT has collaborated with organisations such as [Breakthrough T1D](#) (formerly JDRF) to address health inequalities and barriers to treatment. This has demonstrated that the next crucial step for best practice in health projects is to list 'Romany Gypsy', 'Roma', 'Irish Traveller', 'Scottish Gypsy Traveller' and 'Welsh Gypsy' as distinct and separate ethnic classifications. This would enable the collection of specific data to support further projects and research in line with Core20PLUS objectives, for example, treating children in the communities with diabetes.
- Similarly, whilst disaggregated data monitoring is a significantly better outcome, the Census 2021 ethnicity categories are ready to roll out and further delays will cause more to harm Gypsy, Roma and Traveller people.
- Community members could self-attribute via the NHS app. FFT and sector partners are able to co-produce resources to support swift identification and reach. An example can be seen [here](#).

¹⁷ Public Health Scotland, 2023, *Monitoring racialised health inequalities in Scotland*, p. 35, <https://publichealthscotland.scot/media/19763/monitoring-racialised-health-inequalities-in-scotland-may2023-english.pdf>



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About Us

Friends, Families and Travellers (FFT) is a leading national charity that seeks to end racism and discrimination against Gypsies, Travellers and Roma communities and to protect the right to pursue a nomadic way of life. www.gypsy-traveller.org

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