



The Traveller Movement

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Traveller Movement note on inclusion of Gypsies and Irish Travellers in the NHS data dictionary

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Introduction

In 2011 Gypsies and Irish Travellers were for the first time included as ethnic minority groups in the ONS national census. Romany Gypsies and Irish Travellers are legally recognised as ethnic groups, and protected from discrimination by the Race Relations Act (1976, amended 2000) and the Human Rights Act (1998). Despite this the NHS has no plans to update its National Data Dictionary to include Gypsies and Irish Travellers. A national data change notice issued by the Health and Social Care Information Centre (HSCIC) including these groups would greatly enhance the health services ability to address their health needs. Gypsies and Irish Travellers are recognized by Government as experiencing the poorest health outcomes of any group in the UK.¹

Government position not to update dictionary

The Government outlined their position on this issue in a response by Earl Howe to a question put by Lord Avebury in the House of Lords on 8th January 2013:

'In order to support consistency with other data systems within the National Health Service, ethnicity data for NHS patients are currently collected utilising the 2001 codes. The department, in collaboration with other bodies, will shortly produce guidance that advises on the codes for data collection, including those for ethnicity. The guidance will initially recommend that organisations continue to use the 2001 codes; however this will be revisited biannually with decisions to change this advice based upon the breadth of utilisation of the new coding system.'

NHS organisations can choose to use either the 2001 or the 2011 categories. If they use the 2011 categories, they will need to re-aggregate anyone coming under the "Gypsy and Irish Traveller" heading into "Other" in order to make national

¹ DCLG, 2012, *Progress report by the ministerial working group on tackling inequalities experienced by Gypsies and Travellers*, p. 12

<https://www.gov.uk/government/publications/reducing-inequalities-for-gypsies-and-travellers-progress-report>

comparisons. Additional codes can be included as appropriate at a local level to reflect the demographic make-up of the local population. This allows local monitoring to take place in a way that supports service planning, decision-making, and key processes such as the Joint Strategic Needs Assessments.²

Case in favour of Gypsy and Irish Traveller data change notice

The Government position is contrary to **DH's own internal guidance on ethnic monitoring** which emphasises that it is best practice for NHS ethnic codes to be in line with the most recent Census categories.³ The guidance also outlines the importance of ethnic monitoring in addressing health inequalities experienced by BME groups:

*'The collection and use of ethnic group data on patients, service users, and staff is the foundation on which NHS bodies and councils with social services responsibilities can assess and address health inequalities, difficulties in access and discrimination experienced by some black and minority ethnic individuals and communities.'*⁴

*'The 16 codes are used across Government. Use of the 16 codes helps to maintain consistency between DH central collections and ONS population information. Critically, their use enables ready comparison between NHS and social care information and national and local population counts based on the 2001 census.'*⁵

The case for updating the NHS Data Dictionary to include Gypsies and Irish Travellers has also been made in a **2014 report by Peter J Aspinall for DH's Inclusion Health Board** who are tasked with addressing health inequalities experienced by key vulnerable groups, including Gypsies and Irish Travellers:

*'The ethnic category codes currently used in the NHS Data Dictionary and the Commissioning Data Set Flows are those in the classification used for the 2001 England and Wales Census. Unlike in 2001, there has been no Data Set Change Notice mandating the adoption of the 2011 Census ethnic group classification (which includes 'Gypsy or Irish Traveller'). The adoption of the 2011 Census ethnic category classification in the NHS Data Dictionary would propagate the 2011 classification across all current NHS ethnicity data collections. This would have a transformative effect on the capture of Gypsies/Irish Travellers in routine data collection, including in those areas where there is strong evidence that Gypsies/Irish Travellers are strongly disadvantaged. ISD Scotland has adopted the 2011 classification in the Scotland Data Dictionary.'*⁶

² <http://www.theyworkforyou.com/wrans/?id=2013-01-08a.38.0>

³ DH/Health and Social Care Information Centre/NHS Employers, 2005, A PRACTICAL GUIDE TO ETHNIC MONITORING IN THE NHS AND SOCIAL CARE, para 42
<http://www.lho.org.uk/ViewResource.aspx?id=9743>

⁴ Ibid, page 5

⁵ Ibid, para 35

⁶ Aspinall, 2014, Inclusion Health Board, *Hidden Needs: Identifying Key Vulnerable Groups in Data Collection*, p. 11

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/287805/vulnerable_groups_data_collections.pdf

The Inclusion Health Board's recommendation to the Health and Social Care Information Centre is supported by the **2012 national research report by the Traveller Movement** on the 'Inclusion and ethnic monitoring of Gypsies and Travellers in the NHS.' The report recommended that:

*'DH should issue a national 'data change notice' to include Gypsies and Irish Travellers alongside the 16 +1 other ethnic categories which are monitored by the NHS. This would bring the NHS in line with Gypsy and Traveller inclusion in the 2011 census.'*⁷

The same report also found that approximately 71% of PCT's (before CCG's replaced them) conducted no ethnic monitoring of Gypsies and Travellers, with almost a quarter of respondents (23%) citing non-inclusion in the NHS national ethnic monitoring system as either justification for not monitoring or as an obstacle to greater inclusion and more rigorous data collection.⁸

Conclusion

Gypsies and Travellers face high levels of exclusion and exceptionally poor health outcomes in the NHS. A major reason for this is the general lack of awareness of these groups amongst NHS Trusts and local service providers which is exasperated by non-inclusion in the NHS national ethnic monitoring system.

If the Government is serious about abiding by the **specific legal duties on health inequalities in the Health and Social Care Act 2012**⁹ and its responsibilities under the **NHS Constitution**¹⁰ then it is essential that it makes it a point of urgency to include Gypsies and Irish Travellers in the NHS ethnic monitoring systems.

⁷ Traveller Movement, 2012, *Inclusion and ethnic monitoring of Gypsies and Travellers in the NHS*, page 13

<http://irishtraveller.org.uk/wp-content/uploads/2013/01/ITMB-Health-Report-Inclusion-and-Ethnic-Monitoring-of-Gypsies-and-Travellers-in-the-NHS.pdf>

⁸ Ibid,

⁹ The Health and Social Care Act 2012 contains specific legal duties on health inequalities for the Secretary of State (SoS), NHS Commissioning Board (Board) and Clinical Commissioning Groups (CCG).

*'(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.'*⁹

(Section 14T & 13G)

The new act specifies that CCG's and local authorities must *'involve the people who live or work in that area'* (Section 192). It also places a specific duty on the Secretary of State in *'exercising functions in relation to the health service, the Secretary of State must have regard to the need to reduce inequalities between the people of England with respect to the benefits that they can obtain from the health service'*.

(Section 1C of the NHS Act 2006, as amended by the 2012 Act)

¹⁰ *'You have the right to expect NHS bodies to monitor, and make efforts to improve continuously, the quality of healthcare they commission or provide. This includes improvements to the safety, effectiveness and experience of services.'*

NHS Constitution, page 7

<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf>