



Understanding
Patient Data



UNIVERSITY of
WORCESTER



EQUITABLE DATA COLLECTION FOR GYPSY, ROMA AND TRAVELLER COMMUNITIES IN HEALTH SERVICES

Community-centred and-informed ethnicity
data categorisation

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Executive Summary

Research focus

Given the limited ethnicity data from people of Gypsy, Roma, and Traveller background, this project focused on advancing current knowledge around the barriers that communities regularly face in relation to health and ethnic identity recording. Through direct engagement and co-production, this study generated new insights and thinking around how to meaningfully involve Gypsies, Roma, and Travellers in co-producing ethnic identity-based categories for healthcare services. The aim of the study was to explore community members' perspectives on ethnic categories, ethnic data collection and management in the UK health services to improve active engagement with health services.

Methods

Research methods were underpinned by the principles of co-production, whereby researchers and community members work in authentic partnership from the outset through to dissemination. We established an Advisory Group at the outset of the project and regularly consulted its members regarding the progress of the project.

We had a three-pronged approach to data collection:

- 1) A [desk review](#) of existing research and policies on the topic of ethnic classification in general and as it relates to Gypsy, Roma, and Travellers (Desk Review is provided as a separate document).
- 2) A survey to identify general issues with current ethnic categories in use and best practice recommendations – distributed online through the VideoAsk platform and via hard copies. In total, we had 111 surveys returned. As the survey asked for both quantitative and qualitative responses, descriptive statistics and thematic analyses were used to make sense of the data.
- 3) Focus Group discussions to explore these ideas, concepts and recommendations in more depth – these were conducted in England (5), Wales (2), Scotland (2) and Northern Ireland (2). In total, we had 86 participants producing 606 minutes of voice data which were subsequently thematically analysed.

Key Findings

- 1) *Survey*
 - Out of 103 responses (8 non-responses), a total of 2 (2%) people indicated that their ethnicity was often recorded when using health services, while 25 (24%) noted that their ethnicity was sometimes recorded. As 76 participants (74%) indicated that their ethnicity was never or hardly ever recorded, this information may be helpful in partially explaining the current lack of health data on Gypsy, Roma, and Traveller populations.
 - We asked participants if their ethnicity was listed on forms used by health services. Out of the 64 participants who responded to this question 29 (45%) said yes, 3 (5%) responded sometimes and 33 (50%) reported that their ethnicity was not listed, were never asked, or were not sure. A high number of participants (46) did not respond to this question, which may be because most participants (74%) had never been asked about their ethnicity when using health services.
 - We asked participants if they thought that their ethnicity should be recorded by health services. Out of 104 responses, 76 (73 %) participants noted that recording their

ethnicity would be important or very important, while 8 (7.5%) deemed it somewhat important, 17 (16%) deemed it not important or not very important and 3 (3%) did not know the answer to the question. 7 people did not respond to the question.

- Out of 106 responses:
 - 34 (32%) of the participants identified as Roma (out of which 4 participants added Czech or Slovakian to their ethnic category)
 - 22 (20%) identified as Irish Traveller or Irish or Northern Irish
 - 16 (15%) identified as Welsh Gypsy or Romany Gypsy
 - 14 (13%) identified as English or English Gypsy or Gypsy
 - 8 (7.5%) identified as Scottish Gypsy Traveller (out of which one identified as Nacken¹)
 - 7 (7%) identified as English Traveller
 - 3 (3%) used the combined Gypsy or Irish Traveller category which is still used in the healthcare system
 - 2 (2%) identified as Showman
 - 5 people did not respond to the question.

It can be seen from the data that there are more ethnic categories than currently listed across UK health services and that in many instances ethnic and national identities overlap.

2) Focus Groups

In terms of declaring their ethnic identity within health services, most participants reported **never being asked about their ethnicity** and, when asked, **their ethnicity was often not listed**. This omission was perceived by community members as meaning: 'You are not known here' and 'You are not welcome / do not belong here'. Members in every focus group expressed some degree of reluctance to declare their ethnicity, but it was less prevalent in the three Roma groups. Other main concerns identified by participants were:

- 1) the limited availability of appropriate interpreters (Roma only),
- 2) their own articulations of health needs were not listened to,
- 3) the lack of understanding held by health care staff about their cultural needs,
- 4) the mode of communication between community members and health service providers was often ineffective,
- 5) a preference for working with trusted, local community-run charities to receive essential health information,
- 6) discriminatory experiences of the past still impact how community members interact with people outside of their trust circle,
- 7) general lack of understanding of the need to collect health data.

¹ *Nacken* is a term used by Scottish Gypsy Traveller communities to refer to themselves. The spelling of the word may vary, but it originates from the Cant language.

Main Recommendations

- 1) Collect ethnicity data to justify positive social action and enable health service planning. Communicate reasons for collection to community members at the point of request.
- 2) Self-identification is the generally suggested approach to collecting ethnicity data (see also [Desk Review](#)). If an individual is unable to self-identify at the point of entry to the health service, their ethnic identity, along with other demographic information, should be checked with them as soon as it is practicable.
- 3) Build more meaningful connections with trusted local Gypsy, Roma, and Traveller organisations. Community members have trust in their local advocacy organisations, and they would be more likely to attend health education sessions in those settings. Therefore, to better engage with and reach out to community members, working closely with local Gypsy, Roma, and Traveller organisations is essential. Improving culturally-informed care may also improve willingness and confidence in declaring ethnicity.
- 4) Shift communication with community members about appointments and other health service-related information from a traditional postal letter-based approach (letters don't get delivered/read in time) to phone/text messages. Most community members are adept at using mobile phones as a core means of communication.
- 5) The gender imbalance in the study reflected traditional community perspectives, with participation significantly leaning towards women. Therefore, health services, charities and organisations wishing to engage Gypsy, Roma, and Traveller communities should ensure they plan and carry out health improvements with the active involvement of women from the communities.

The recommended ethnic categories based on data collected from target communities and feedback sought from the AG are:

- English Gypsy/Romany
- Irish Traveller
- Scottish Gypsy Traveller
- Welsh Gypsy/Romany
- Roma
- English Traveller

Background and introduction

A brief historical background to Gypsy, Roma, and Travellers

Nomadic people were probably well established in Britain by about 1000 A.D. and these included English Gypsies, Welsh Gypsies, Scottish Gypsy Travellers and Irish Travellers. In the late 1400s Roma people began arriving in Britain, having originated in India (Travellers Times, 2019). The categorisation of groups is complex and contested, some groupings preferring the word 'Romany' to 'Gypsy' as in 'English Romany' and 'Welsh Romany', and sometimes the word 'Roma' is used to include all the above cultures under the one umbrella term. 'Romani' is a term also sometimes used to represent English Gypsies, Welsh Gypsies, Scottish Gypsy Travellers, and Irish Travellers. 'Gypsy' is regarded as a derogatory word in much of Europe but in Britain it is an acceptable term (McLaughlin, 2008). The abbreviation 'GRT' is not seen by communities as an appropriate term as it homogenises their distinct cultures, instead of recognising their differences (Hulmes & Unwin, 2024). Over the centuries all these group have suffered various forms of discrimination as their fortunes and lifestyles have changed. Only a very small minority are now nomadic, partly because modern workforces, such as in agriculture, no longer require large numbers of itinerant workers and legislation, such as The Police Criminal, Sentencing and Courts Act (2022) has sought to criminalise the nomadic way of life (Hulmes & Unwin, 2024).



Roma tend to be 'settled' once in Britain and live in 'bricks and mortar', usually concentrated in cities and large towns with greater employment opportunities. The National Census (2021) reported that, in England and Wales, 78% of English Gypsies, Welsh Gypsies, Scottish Gypsies and Irish Travellers also now live in 'bricks and mortar' with 22% living on sites in chalets or caravans. There are also a very small number of Romani who live 'roadside' and do still travel year-round.

In respect of the health outcomes of Gypsies, Roma, and Travellers, these are variously acknowledged (Friends, Family and Travellers, 2022) as being poorer than any other ethnic minority groups in the UK, although statistical data relating to Gypsy, Roma, and Travellers is almost always incomplete, due largely to fear of declaring ethnicity. Whilst data on health outcomes for Gypsies, Roma, and Travellers is sparse, historical reporting (e.g., House of Commons Women & Equalities Committee, 2019; Sweeney & Dolling, 2020; Unwin et al., 2023) is consistent in its claims that their health outcomes are among the poorest of all ethnic minorities, with very high levels of mental and physical ill-health. Such reports and policy documents have recognised serious health inequalities, along with systemic discrimination, lack of education, and economic deprivation (Unwin et al., 2020). Despite multiple reports, the wider determinants of health, such as quality of life, literacy levels, employment opportunities and economic conditions for Gypsies, Roma, and Travellers appear to continue to decline.



Introduction to the project

The need for accurate data collection has been noted by many reports in relation to the health of Gypsies, Roma, and Travellers (e.g., House of Commons Women & Equalities Committee, 2019; Unwin et al, 2023; GATE Herts, 2024; UK Health Data Research Alliance, 2024), yet only limited advancement has been made in this area. Whilst the 2021 National Census included 'Roma' as distinct ethnic category for the first time, alongside a combined 'Gypsy or Traveller' option, NHS data collection relating to patients' cultural identity has remained dated despite recommendations by a report commissioned by Inclusion Health (Aspinall, 2014). This report emphasised the challenges in gaining an accurate sense of the health needs of Gypsy, Roma, and Traveller communities at both national and local levels because of their absence in standardised datasets. Obtaining such information was seen as crucial if unmet health needs were to be successfully addressed. Effective service development and deployment was seen as ineffective without better quality and more granular information on the range of the specific health needs of Gypsies, Roma, and Travellers, whose lifestyles were often very different to most of the UK's population. Aspinall (2014) 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 GEPS has only a Traveller category. Consequently, data on Roma is absent in both GPES and HES, and data on Gypsy and Travellers are absent in HES and minimal in GPES (ONS, 2024).

Aspinall (2014, p.16) referred also to the Joint Strategic Needs Assessments (JSNAs) which had identified Gypsies and Travellers as a particularly vulnerable group due to:

- (i) The difficulties these groups experience in accessing health services generally and primary care, in particular;
- (ii) These groups suffering multiple and enduring disadvantages and, thus, their health outcomes being the worst of any ethnic group;
- (iii) The deprivation of opportunities that are readily available to the wider society, stemming from discrimination, ostracism, and racism.

Aspinall (2014) also noted apprehension in approaching health services and concluded that it was particularly important for Gypsy and Traveller populations that their use of health services, birth outcomes, maternal morbidity and mortality, childhood immunisation rates, and mental health are appropriately captured in both local and national health data.

The NHS, like other public services, should ideally have a workforce that represents the communities it serves. In terms of ethnic diversity, this is also measured using available ethnicity data. The NHS England Workforce Race Equality Standard (WRES) report (2024) indicates that the health service is more ethnically diverse than ever before, which is a sign of progress in reducing inequality and ethnicity-based attainment gap. However, not all ethnic minorities are equally represented in the NHS workforce and Gypsy and Traveller NHS staff are the most likely to experience harassment and bullying from patients and other staff members. For instance, NHS England (2023) reported that 48 percent of women staff from a "white Gypsy or Irish Traveller" background experienced harassment, bullying or abuse from patients, relatives, or the public. The report also notes that NHS England staff from Gypsy or Irish Traveller background experience the highest level of harassment, bullying or abuse from other staff. Whilst staff experiences are not the focus of this report, this helps to build a picture of the Gypsy, Roma and Traveller experience of the NHS from different angles.

It seems that unwelcoming healthcare settings are experienced by Gypsies, Roma, and Travellers whether employee or patient (see Unwin et al., 2020). Patients from Gypsy, Roma, and Traveller backgrounds must also contend with challenges around registering with a GP, accessing relevant forms, and having limited health literacy. Van Cleemput et al. (2004) previously found that GP registration rates were low, often related to lack of proof of identity, lack of a permanent address, poor literacy, and limited ability to use English (for Roma). Parry et al. (2007) noted that 16% of Gypsies and Travellers were not GP registered and were also less likely to visit the practice nurse, a counsellor, chiropodist, dentist, optician, or alternative medical workers, or to contact NHS Direct (now NHS 111) or visit walk-in centres than any other social groups.

Furthermore, the recent passing of the Police, Criminal, Sentencing and Courts Act (2022) has compounded the general atmosphere of Gypsies and Travellers not being welcome in wider society as this Act criminalises a nomadic way of life that has been practiced by members of these communities for centuries. This Act reflects societal oppression and discrimination that provides the backdrop for the physical and mental health issues experienced by Gypsy and Traveller communities. Most policies and legislation in recent decades have been created without input from Gypsy, Roma, and Traveller communities. This is the case across the current healthcare and social care policy landscape, which may additionally deter members of Gypsy, Roma, and Traveller communities from revealing their ethnic identities (The Traveller Movement, 2017).

Other dimensions of social deprivation include the environmental circumstances of Gypsy and Traveller sites across the UK. Quarmby (2020) regarded their conditions and locations as a form of environmental racism and a national scandal. One Cardiff site was condemned by the council in 1973 due to contamination but was deemed suitable for Gypsies and Travellers (Quarmby, 2020). Being forced to live in environmental conditions which are deemed unsuitable for the general population reinforces feelings of being ostracised and is a further factor which prevents members of the target communities from revealing their identities. Living under such conditions would also undoubtedly have an impact on their health.

GATE Herts (2024), a charity focusing on supporting Gypsy and Traveller communities, recently reported that the main reasons for limited ethnic monitoring of Gypsies, Roma, and Travellers in the health sector are:

- Lack of cultural awareness;
- Limited community engagement;
- Language and literacy challenges;
- Fear of discrimination;
- Limited data collection infrastructure.

Given the limited ethnicity data from people of Gypsy, Roma, and Traveller backgrounds, this project focused on advancing current knowledge around the barriers that communities regularly face in relation to health and related ethnic identity recording. Through direct engagement and co-production, this study generated new insights and thinking regarding how to meaningfully involve Gypsies, Roma, and Travellers in co-producing ethnic identity-based categories. The aim of the study was to explore community members' perspectives on ethnic categories, ethnic data collection and management in the UK health services to improve active engagement with health services. This study accords with the principles of the Public Sector Equality Duty (Equality and Human Rights Commission, 2022) and is built on the ethos of eliminating discrimination, harassment and victimisation, by addressing the specific needs of individuals from protected groups and actively encouraging individuals from protected groups to participate in resolving issues around the ethnic monitoring of Gypsies, Roma, and Travellers.

Research Objectives

Gypsy, Roma, and Traveller communities in the UK have been historically marginalised and underserved by health and social care services and have not benefitted from advancements made in healthcare and health education. These communities continue to experience multiple deprivations across society, including inferior access to healthcare resources. Healthcare-related inequalities are intensified by a lack of granular data on, and tailored health services for, Gypsy, Roma, and Traveller communities. Consequently, they have exceedingly high levels of health concerns and shorter and unhealthier lives than all other ethnic minorities in the UK (GATE Herts, 2024).

This project actively engaged members of Gypsy, Roma, and Traveller communities across the UK in a co-produced project to improve the current system of ethnic categorisation. To achieve this goal, we adopted a participant-informed and participant-led approach that built on lived experience and cultural knowledge. A participant-informed methodology is essential when working with marginalised communities where traditional researcher-centred approaches are still dominant and less effective. Therefore, we actively involved community members in all key stages of this research project from developing the original bid, designing the data collection tools, through facilitating interviews to writing up the findings. Our main objectives were also underpinned by the principles of co-production, as follows:

- 1) To identify, access and recruit members of Gypsy, Roma, and Traveller communities through voluntary organisation across the four nations of the UK. These encompassed members from English Gypsy, Scottish Gypsy Traveller, Welsh Gypsy, Irish Traveller, Showmen, and Roma communities;
- 2) To establish and maintain a project specific Advisory Group (AG) for the duration of the project to inform best practice in patient-centred data collection and categorisation;
- 3) To establish and maintain an Impact Board for the duration of the project to explore maximisation of project impact;
- 4) Co-produce ethnic identity centred focus group questions and a survey;
- 5) To recruit Gypsy, Roma, and Traveller participants to complete a co-constructed questionnaire and participate in focus group discussions, which included topics such as revealing ethnic identity, preferred ethnic identity, and issues surrounding data management and storage;
- 6) To analyse and report findings in ways which are useful and accessible to all beneficiaries with a view to co-produce recommendations for ethnic categorisations across UK health services.



Methods and Data Collection

Research methods were underpinned by the principles of co-production, which involves researchers and community members working in authentic partnership from the outset through to dissemination (Unwin et al., 2020,2023; Sealey et al., 2021). Such an ethos was intrinsic to our research approach as we wished to challenge traditional hierarchies of power and privilege and to promote equitable and reciprocal outcomes (Boyle and Harris, 2009). This meant that flexibility and negotiation were important at every stage of the process. We were committed to engaging in continuous and meaningful discussions with members of the target communities throughout the life of the project and beyond to ensure that we delivered the most impactful evaluation for all concerned. Furthermore, the balance of the research team was strongly weighted towards community members as co-researchers (2:6 ratio). We carried out a three-pronged approach to data collection:

- a) We carried out a desk review exploring existing research and policies on the topic of ethnic classification in general and as it relates to Gypsy, Roma, and Travellers. To search for relevant sources that focus on ethnic categorisation and issues around that, we executed a systematic scoping review. Scoping reviews enable researchers to examine central issues surrounding a research area and discover key sources and types of evidence available (Tricco et al., 2018), without being restricted by a potentially narrow range of quality-defined studies and by different methodological approaches used. In accordance with scoping review recommendations (Peters et al., 2015), we used broad research questions combined with clear definitions of the concepts relevant to the study's scope (for full description and results of the review process please see [Desk Review](#)).

We discussed the key findings of the review with the AG and sought feedback. While the desk review did not directly influence the generation of research tools and data collection, sources identified through the review process feature in our data interpretation sections. A review of existing ethnic classification templates currently used in the health services in the UK is also included in the Desk Review document.

- b) With input from the AG, we produced a set of questions for the survey to collect demographic data, capture views about preferred classifications and the ways in which NHS staff might best approach asking about preferred classification (See Appendix 1). We sought to identify general issues with current ethnic categories in use and best practice recommendations. The survey was distributed in hard copy format at focus groups and electronically through the VideoAsk platform (Figure 1). We were aware of the challenges associated with surveying Gypsy, Roma, and Traveller communities and to overcome some of those we used the VideoAsk platform which allowed questions to be put to participants in a video recorded format. The platform also allowed participants to respond to survey questions in writing or by recording their voice responses. These aspects of the survey were implemented to help eliminate potential issues with traditional lack of engagement with surveys.

We sent the VideoAsk survey link to our local and national Gypsy, Roma, and Traveller networks for distribution, and we also shared the survey link on Twitter (now X) (Note: ethical approval was gained from the University of Worcester – ethics code: HS23240038-R - before primary data collection). Interestingly, the survey distributed through the VideoAsk platform collected only 21 replies, whereas we received 90 hard copies, totalling 111 survey returns. As the survey asked both quantitative and qualitative questions, descriptive statistics and thematic analyses were used to make sense of the data.

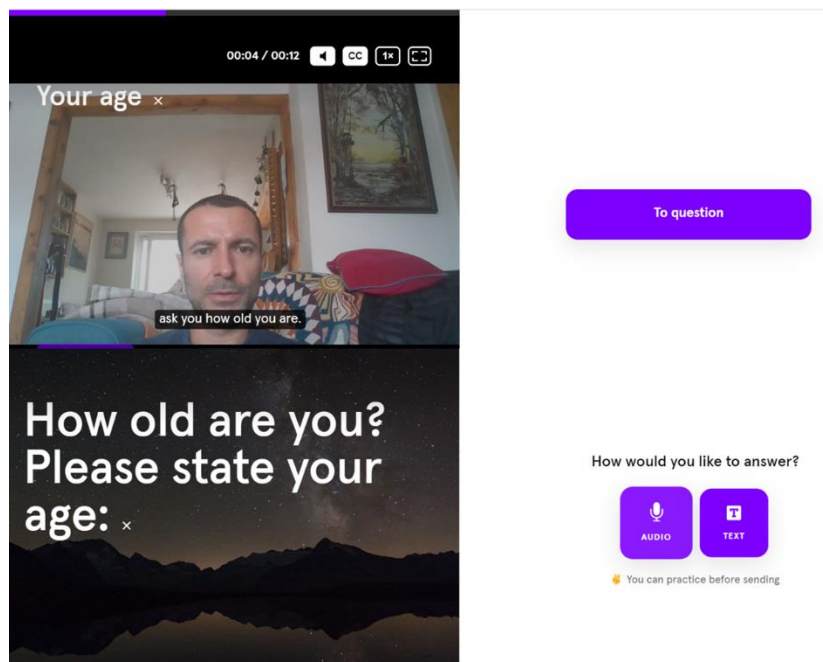
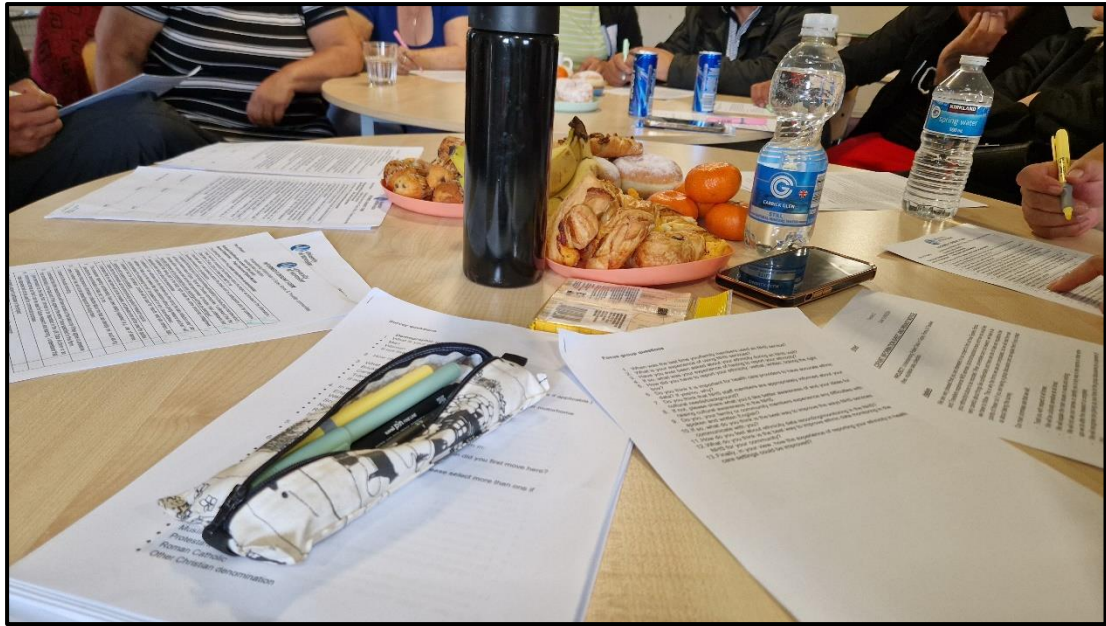


Figure 1: Screenshots from the VideoAsk platform

c) For focus group-based data collection, we identified Gypsy, Roma, and Traveller communities across the UK through preliminary discussions with members of the AG. We approached suggested community members through our existing networks and members of the AG. At the outset of the research, we established connections with the following communities:

- England – Lincolnshire Traveller Initiative, Leeds GATE, GATE Herts, York Travellers Trust, Sheffield Roma, Rotherham Roma;
- Scotland – Pitlochry (Scottish Gypsy Travellers) and Romano Lav (Roma) in Glasgow;
- Wales – Travelling Ahead (Welsh Gypsies);
- Northern Ireland – Armagh Traveller Initiative (Roma and Irish Travellers).

Focus group questions were co-produced with input from the AG. Focus group interviews took place across the four nations in the UK and were held in person. They were facilitated by two research team members, one of whom was from a Gypsy, Roma, or Traveller community. We held a total of 11 focus groups with 86 participants: two in Northern Ireland, two in Wales, two in Scotland and five in England. A maximum of eight participants were sought for the focus groups and attendees were remunerated for their time in accordance with best inclusion practice (e.g., BASW, 2020). Focus group-generated voice data was transcribed using OtterAI, reviewed by team members, and subsequently thematically analysed (Braun and Clarke, 2021). Data analysis and interpretation was extensively discussed with members of the AG and this report and recommendations therein regarding ethnic categorisation built on feedback both from the AG and the Gypsy, Roma, and Traveller communities who participated in this project.



In the sections below, we discuss findings derived from both the survey and the focus group data and provide recommendations for the most appropriate approach to ethnic categorisation regarding Gypsy, Roma, and Traveller communities in health services, and which could also be taken up elsewhere by other organisations which collect data.

Findings

In this section we have included two sub-sections which focus on the two main primary data sets we collected during the course of this project, namely: a) survey data and b) focus group data.

Survey Data

Demographic information

The survey contained both quantitative and qualitative questions (please see Appendix 1). It began with nine demographic questions focusing on gender, age, religion, accommodation, country of origin, country of residence, moving to the UK (for Roma), languages spoken and grown up with, occupation and highest educational qualification.

In terms of gender, 95 females and 13 males (note that percentages were rounded to the closest whole number where possible) completed the survey (Table 1). The fact that women were more willing to engage with the survey reinforces previous observations about the target communities in terms of gender differences (Unwin et al., 2023). The average age of the participants was 47.5 years (2 no response - NR) with the oldest being 73 years and the youngest 18 years. Participants reported living in a range of accommodation types, but with the majority in bricks and mortar or bungalow, or caravan or chalet on a site (Table 2).

Table 1. Gender demographics

Gender	n	%
Male	13	12
Female	95	88
No response	2	

Table 2. Accommodation demographics

Accommodation	n	%
Bricks and mortar or bungalow	53	51
Caravan or chalet on a site	38	36
Flat	2	2
House or chalet but travel part of the year	2	2
Homeless	2	2
No response	6	

42 (38%) of the participants were born in England, 10 (9%) in Scotland, 8 (7%) in Wales, 6 (5%) in Ireland, 12 (11%) in Northern Ireland, 18 (16%) in Slovakia, 7 (6%) in Bulgaria, 4 (3%) in Czech Republic, 2 (2%) in Romania and 1 (0.9%) in Belgium (1 NR). 38 participants gave a date for moving to the UK, out of which 6 moved from Ireland and 32 from various other European countries. People moving from Ireland arrived in the UK between 1969 and 1986, whereas people moving from Europe arrived between 2005 and 2022, after the 1st of May 2004 EU enlargement project. 62 (56%) of the participants lived in England, 19 (17%) in Northern Ireland, 18 (16%) in Scotland and 11 (10%) in Wales (1 NR). Participants reported having a range of religious affiliations, but with the majority being Roman Catholic, Christian and Protestant (Table 3).

Table 3. Religious affiliation

Religion	n	%
Roman Catholic	43	39
Christian/other Christian denomination	38	35
Protestant	10	9
had no religion	2	1
Church of England	1	.9
Baptist	1	.9
Buddhist	1	.9
Jehovah's Witness	1	.9
Zoroastrian	1	.9
No response	2	

The next question in the survey probed the languages participants spoke whilst growing up. 66 (63%) participants indicated that they had spoken multiple languages whilst growing up, which included a combination of the following: English, Welsh, Romani/Romanes, Polari, Pogadi Chib, Cant, Gammon, Gaelic, Slovak, Czech, Romanian, Bulgarian, Hungarian, Russian, German, and Polish (6 NR). 39 Participants noted that they grew up with only one language which included English (29, 27%), Slovakian (3, 3%), Irish (3, 3%), Cant (2, 2%) and Bulgarian (2, 2%).

Table 4 outlines participants' occupations - out of all the participants who responded to this question, 17 included multiple occupations such as part-time employed and carer, part-time employed and student, looking after family and between jobs, part-time employee and long-term sick. When participants included multiple categories, their first choice was considered as their main occupation, which is represented in Table 4.

Table 4. Occupation

Occupation	n	%
Looking after home and family/informal carer	28	27
part time employee	24	23
full time employee	20	19
Long-term sick/disabled	16	15
Retired	5	5
Unemployed	5	5
Studying	4	4
Self-employed	2	2
No response	7	

Participants had a broad range of educational qualifications, but most of them (52, 50%) had no formal qualifications. Table 5 displays all participants' educational qualifications. It should be noted that as Roma participants would have completed some or all their education in their country of origin, their education pathways do not map directly onto the qualifications offered in the UK. Therefore, some of the Roma participants stated primary school, high school, and apprenticeship completions.

Table 5. Educational qualifications

Level of education	n	%
no formal qualification	52	50
Primary school	10	9
GSCE or equivalent	8	7.6
High school	8	7.6
Postgraduate education	7	7
Professional qualification	7	7

Graduate education	6	6
NVQ or equivalent	4	4
Apprenticeship	2	1
No response	7	

Ethnic and national identity

One of the main foci of the survey was to explore participants' ethnic identities. As ethnic and national identities can be connected, we also asked participants to indicate both their ethnicity (Table 6) and national identity. We were also interested to know whether participants' ethnicity was recorded when using health services, whether their ethnicity was listed in health service forms, whether their ethnicity should be recorded by health services and, if their ethnicity was not listed, what their preferred ethnicity would be.

Table 6. Preferred ethnicity

Ethnicity	n	%
Roma	34	32
Irish Traveller, Irish, Northern Irish	22	20
Welsh Gypsy, Romany Gypsy	16	15
English, English Gypsy, Gypsy	14	13
Scottish Gypsy Traveller (one Nacken)	8	7.5
English Traveller	7	7
Gypsy or Irish Traveller (combined category)	3	3
Showman	2	2
No response	5	

It can be seen from the data presented in Table 6 that there are more ethnicity categories than currently listed across UK health services and that in many instances ethnic and national identities overlap (Table 7).

Table 7. National identity

National identity	n	%
British, English, Northern Irish, Scottish or Welsh	56	53
European*	23	22
Irish, Irish Traveller	14	13
Slovakian, Slovakian Roma	7	7.5
Czech	2	2
No national identity	2	2
Romanian Roma	1	1
No response	6	

* Those who identified as European were of Roma background

Participants were also asked to indicate if their ethnicity was recorded when using health services in the UK. 2 (2%) people indicated that their ethnicity was often recorded when using health services. 25 (24%) noted that their ethnicity was sometimes recorded and 76 (74%) indicated never or hardly ever (8 NR). As most participants (74%) never or hardly ever had their ethnicity recorded, this information may be helpful in partially explaining the current lack of health data on Gypsy, Roman and Traveller populations.

We asked participants if their ethnicity was listed in forms used by health services. 29 (45%) participants responded yes to the question, 3 (5%) responded sometimes, 33 (50%) believed that their ethnicity was not listed, or were never asked or were not sure. A high number of participants did not respond to this question (46 NR), which may be because most participants (74%) had never been asked about their ethnicity when using health services.

Survey respondents were asked if they thought if it was relevant for health services to have accurate information about patients' ethnic identity. 76 (73 %) participants noted that recording their ethnicity would be important or very important, 8 (7.5%) deemed it somewhat important, 17 (16%) deemed it not important or not very important and 3 (3%) did not know the answer to the question (7 NR).

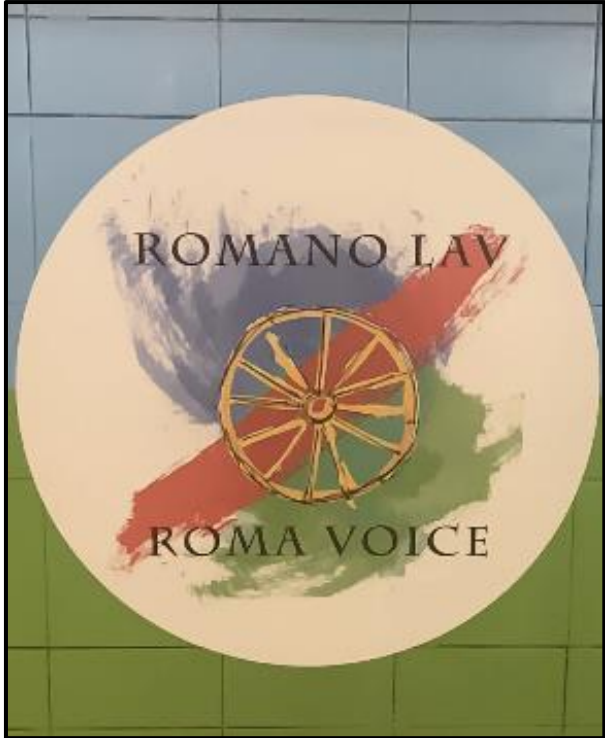
Survey respondents were asked to state their preferred ethnic identity that should be listed across health services in the UK. Participants stated a very broad range of preferred ethnic identities (see Table 8).

Table 8. Participants' preferred ethnic identity in health services

Preferred ethnic Identity in health services	n	%
Roma	22	28
Irish Traveller (one stated Pavee*)	12	15
Romany	7	9
English Gypsy	6	8
Scottish Gypsy Traveller (one stated Nacken)	6	8
English Traveller	4	5
Northern Irish	3	4
Romany Gypsy	3	4
Traveller	2	3
Welsh Gypsy/Welsh Romany (one listed Kalo Romani)	2	3
Gypsy	2	3
Showman	2	3
Slovak Roma	2	3
Don't want to be different	2	3
Gypsy or Irish Traveller	1	2
English	1	2
Irish	1	2
Bulgarian	1	2
No response	32	

* Pavee comes from the Traveller language *Sheelta* and refers to members of the nomadic communities in Ireland.

While it is not possible to accommodate all the preferred ethnicities listed by the survey participants, in the *Recommendation* section we make clear suggestions for ethnic categories to be included in health services across the UK based on primary data collected in this project and input from the AG members. It is also important to note that we had a high non-response rate (32) to this question, which might be due to some of the participants deeming the question redundant as a previous question asked them to self-identify their ethnicity. Therefore, participants' response to the question to self-identify their ethnicity was also considered when making recommendations (see *Recommendations*).



Engagement with health services

We also asked participants about their engagement with health services across the UK. We were interested to know how frequently they used health services, how comfortable they were talking to health professionals in English, what their experience of using health services was, and whether health services were appropriately informed about their cultural needs. Participants' reported frequency of using health services is shown in Figure 2 (5 NR).

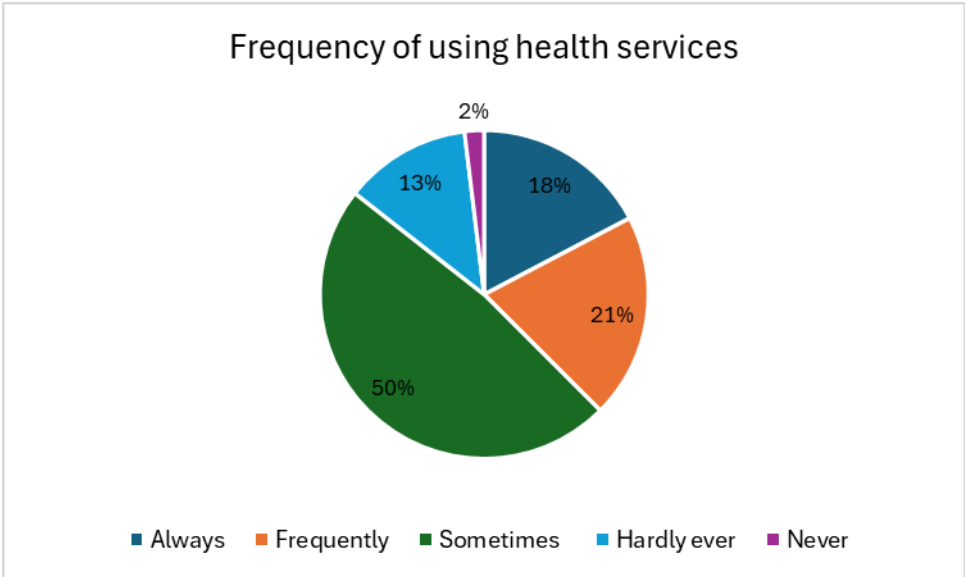


Figure 2. Participants' reported frequency of using health services

Participants' reported quality of experience when using health services is shown in Figure 3 (10 NR).

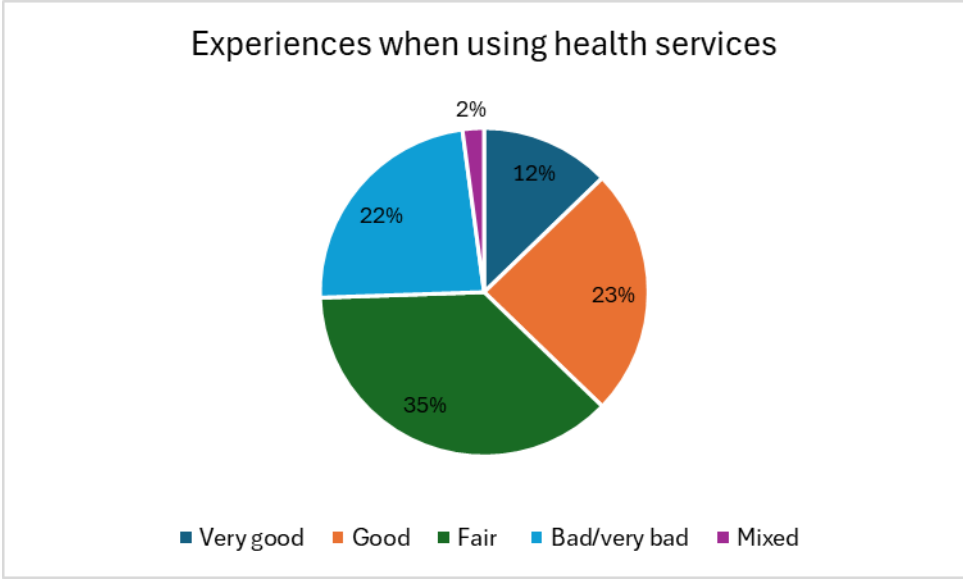


Figure 3: Participants' reported quality of experience when using health services

We asked respondents to explain their experiences regarding using health services. We received a broad range of replies, for instance, people who had good or very good experiences using health services provided explanations such as:

- “GP listens to family.”*
- “They always listened and helped.”*
- “Been helpful when I needed them; they looked after my son’s Type 1 diabetes well.”*
- “Overall, I feel very lucky to have access to the National Health System... [but] NHS dentists are becoming increasingly more difficult to find which is worrying.”*
- “I’ve had cancer and they’re keeping me alive. I’ve had several major illnesses in the past and I’ve been grateful for their help and expertise.”*

Participants who had fair or mixed experiences of using health services reported the following:

- “Some hospitals are good, others I am afraid of. Receptionists can be horrible if you say you are a Gypsy.”*
- “Current GP is respectful. Previous bad experiences especially with receptionists asking for personal information in public.”*
- “Sometimes nice; sometimes rude. It really depends if they like Travellers or not.”*
- “Not always listened to- sometimes made to feel you are a hypochondriac exaggerating symptoms.”*
- “It’s hard to get past frontline staff, they don’t understand our culture.”*

Participants who had bad or very bad experiences when engaging with health services made the following comments:

“Two racist receptionists - my local surgery is hard work. I don't like the hassle and when I get through, they put the phone down.”

“Can't bear going. They are too ignorant and don't treat me well.”

“No appointments available.”

“Lack of professionals' interest in Travellers plus unwillingness to allocate resources, viewed as better spent on other patients.”

We also asked participants to what extent they were comfortable with talking to health professionals in English (Figure 4) (6 NR).

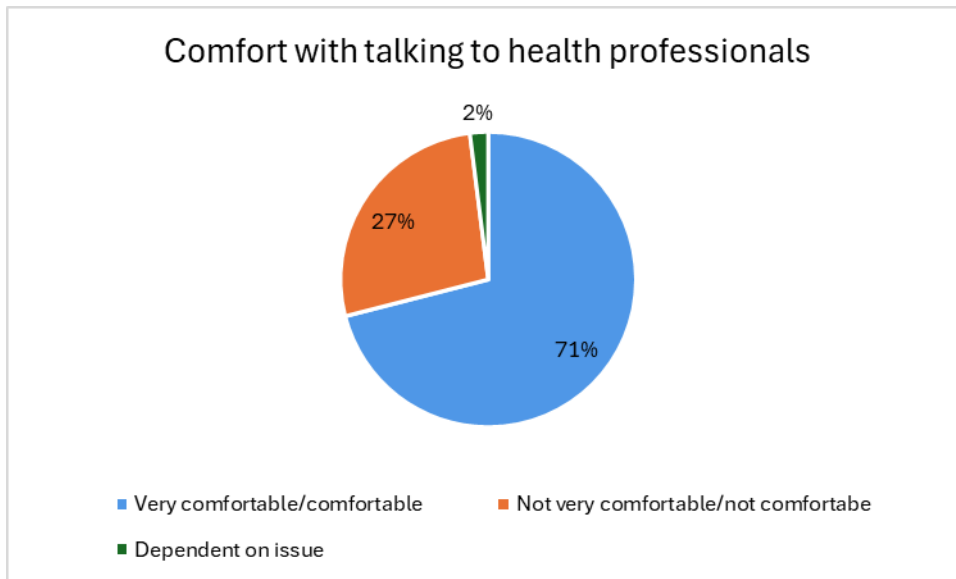


Figure 4: Participants' reported comfort with talking to health professionals

It is pertinent to note that while 71% participants felt very comfortable or comfortable talking to a health professional in English, only 34 (45%) participants indicated English as their main language and 42 (55%) declared that their main language was other than English. It is also worth noting that we had a high non-response rate to the category of main language used (NR 36), which may explain the discrepancy between the figures.

Participants were asked to share their views on how well-informed health services about their cultural needs and background (Figure 5) (7 NR).

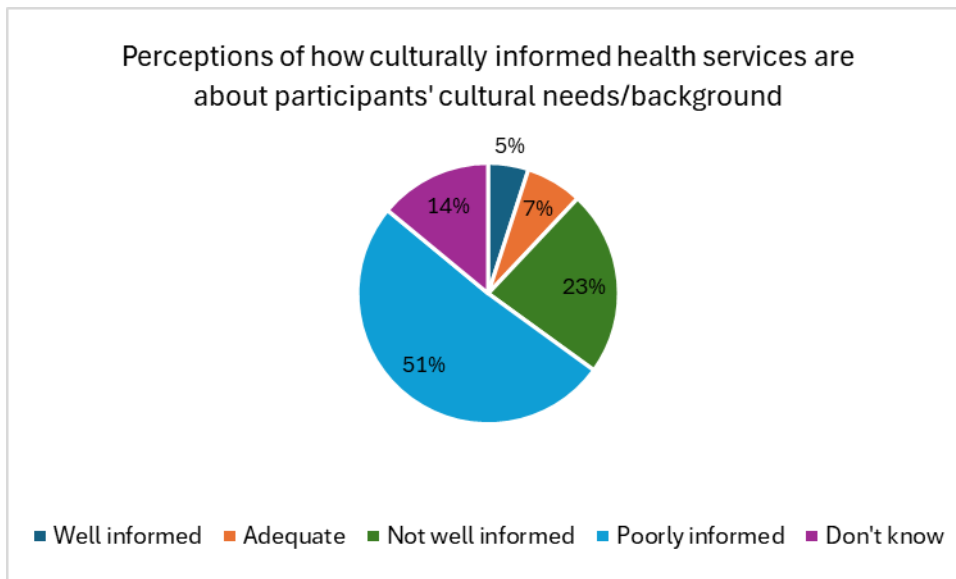


Figure 5: Participants' perceptions of how health services' cultural awareness

To further probe this, we asked them to outline what they would expect health services staff to be aware of about their cultural needs. To this question, we received 72 responses (39 NR) which outlined participants' expectations, examples of which are listed below:

“To know what it means to be a Traveller, what it means to be a Gypsy woman.”

“I find it hard to talk to a male doctor. It is embarrassing to talk to a male gynaecologist. Not culturally allowed to talk to a man about such things.”

“Respect that we are valuable, [and our] lifestyle.”

“To understand that we are a travelling community, live in chalets and trailers, can't drop the work quickly to make appointments, especially in the summer months.”

“That we have specific needs that differ from the wider public. That we have a language that when describing ill health may differ [from professional language].”

“That no matter how you identify, you are still ill and no different to others.”

“Need to listen to people/families. Try to have compassion for families; Understand that there is difference between 'Gypsy' and 'Slovak'.”

“Customs around visiting hospitals when family are very sick or dying.”

“Should know about cultural taboos.”

“To know what we [women] won't discuss if a man is present.”

“That we are not like 'Big Fat Gypsy wedding' - they don't understand our heritage.”

“My main issue is the stereotypes that are believed by some NHS staff members. No, we're not all violent and not everyone who is a Gypsy or a Traveller is 'traditional'. The security that works within NHS hospitals are usually the worst culprits.”

“We would like translators to be available [for Roma].”

Generally, the above comments demonstrate that participants would like healthcare staff and services to have more respect for their culture and better acknowledgement of their cultural needs. Those cultural needs include, for instance, awareness of cultural taboos, women to have access to female physicians, to be aware of cultural differences such as community members' description of illnesses and families visiting relatives in hospital. Participants also noted issues around existing stereotypes that seem to impact on their experience in the health services and expressed the need to eradicate such cultural labels from health services as those do not apply to most community members. For Roma, who migrated to the UK and, thus, may struggle with speaking English, having people who can translate would also be helpful (Note: Roma are often discriminated in their home country, and it needs to be ensured that translators do not hold racist feelings towards Roma people). We will further discuss cultural issues for Gypsy, Roma, and Traveller community members in Focus Group Data section.

Future research to be carried out

We also asked participants if they thought that more research should be carried out in their communities in the future and if so, what that research should focus on. 81 (86%) participants supported the idea that more research in their communities should be carried out. Out of the 81, two added additional comments: 'Yes, because we are dropping off like flies' and 'Yes, but co-produced with community members'. Eleven (12%) participants did not think more research would be necessary and 2 (2%) did not know whether more research should be carried out (17 NR).

To the question about the focus of future research 56 (50%) participants did not respond, but we had a broad range of responses from 55 (50%) participants. Their responses revolved around the following suggestions:

- Cultural awareness and cultural sensitivity;
- Awareness raising of health services about health conditions frequent in communities;
- How to build trust with communities;
- Mental health and suicide prevention;
- Childbirth and women's health;
- Substance abuse;
- Registering and getting appointments.

Participants also included comments that were not supportive of having more research carried out in their communities:

'There's enough research, action is needed to close known inequality gaps.'

'We [are] sick of people with the papers and pens. We don't need research, just understanding that's all.'

Comments indicate strong dissatisfaction with the actual impact of research that had been carried out in communities as participants experienced no qualitative differences in their life after providing information for research purposes. One respondent aptly summarised community members' weariness of outsiders:

"We struggle with speaking outside our community. We suffered decades of judgement, discrimination, not being listened to or understood. Even if we do speak out, we are often dismissed especially when trying to talk to health professionals. Instead of listening they dismiss us and invalidate us and tell us how we are feeling. So, we shut down and suffer in silence and fend for ourselves. We always get treated differently."

Given the experiences many community members have regarding using health services across the UK, what they wish for is captured by one of the survey respondents:

“To be more compassionate about our culture - to be aware of our health inequalities - to study our history/culture - less discrimination - accessibility - [less] waiting time - to understand that many of us are coming with baggage of negative health experiences, witnessing death, children born with different health issues.”

In this sub-section, we presented our findings from the survey-based data collection. Most of the data presented were quantitative and reflect that a broad range of participants engaged with the survey. A key finding was that most of the participants did not have their ethnic identity registered and that their preferred ethnic identity was not listed when using health services. The responses also revealed that participants have a much broader range of ethnic identities than current list of ethnic categories used in health services across the UK. It is also worth noting that whilst most participants agreed that more research should be carried out about their communities, some of the respondents were disillusioned with research and the benefits of that for their communities. We also presented some qualitative data from the survey which reflected how some respondents felt about research and health services in general. Whilst the quantitative data, along with the quotations from the survey, offered a broad picture of the current state of the perceptions of Gypsy, Roma, and Travellers about their ethnic identity and the health services, more granular qualitative data are presented in the next sub-section.

Focus Group Data

The interview quotations included below represent key themes from the transcribed audio data. Themes identified during analysis are **emboldened** and are not attributed to any particular focus group to ensure anonymity, but it is indicated where a specific issue is relevant to one of the ethnic groups. Some quotes have been slightly altered for reasons of confidentiality and anonymity, but the original meaning was retained. It is also pertinent to note that out of the 86 focus group participants, 76 were women. This gender imbalance reflects traditional cultural perspectives and likely had an impact of discussion in focus groups.

Why and how community members prefer to have their ethnicity recognised and categorised by the NHS were noted across all focus groups. These views ranged across the spectrum from “I am proud to declare that I am a Gypsy” to “I would never state my ethnicity – it would only lead to bad things”. The latter explanation was the most frequent, which indicates that most participants would not wish to disclose of their ethnic identity due to fear of discrimination. This may be viewed as **the legacy of past discriminatory experiences** within the NHS, which remains a present issue, particularly for Gypsies and Travellers.

Roma, who arrived in the UK from Central and Eastern Europe after the 2004 EU enlargement, spoke less of discriminatory experiences once they accessed NHS care and were concerned less about issues of ethnic categorisation (most accepted ‘Roma’ when it was proffered). Roma participants were more focused on the accessibility difficulties of digitalised systems, waiting lists and a lack of appropriate interpreters.

The topic of ethnic categorisation was not the subject which held the most interest for the focus group participants once the surveys had been completed. Instead, discussions tended to veer towards the types of issues also experienced by the general public in respect of health services in the UK, e.g., long waiting times and the increasing digitalisation of services. These issues are compounded for members of Gypsy, Roma, and Traveller communities who described how discrimination affected both their attitude and access to services and the health treatment they received. A mixture of views emerged, with some

healthcare staff being seen as helpful and supportive although most participants reported unhelpfulness and discriminatory attitudes.

Regarding **being asked about their ethnicity**, many of the focus group members could not remember being asked about ethnicity, or it had been assumed by health professionals or receptionists that they were White British or from an ethnicity different to the one they would have been given. One participant explained how healthcare staff may erroneously identify their ethnicity:

“I want my ethnicity known so doctors, so they don’t assume I’m Irish or Traveller like that one the other day. He asked me if I was from Belfast, and I told him I was a Welsh Gypsy and nothing else. He asked if I was sure, as if I don’t know who I am. Do I sound Irish to you?”

A particular issue around ethnicity recording was **absent categories**. When a community member was asked about their ethnic background, the specific terminology they would have liked to have seen was often not present. For example, there was a reluctance to tick ‘Gypsy’ if a person self-identified as a ‘Traveller’ and vice-versa. A participant explained the importance of having the right ethnic categories:

“Definitely don’t want to see ‘Gypsy and Traveller’ together. I want a distinction between ‘Gypsy’ and ‘Traveller’. They are completely different. I want a choice. If there is a choice I will choose ‘Gypsy’.”

Most participants wanted to be known in ways that reflected their ethnicity, rather than aggregated with other cultures. The only exception to this was participants’ views in Scottish focus groups, who expressed that they would want to be known as Scottish Gypsy Traveller, with one participant suggesting that he would prefer the term *Nacken*.

The debate about whether it was a good and moral thing to have one’s ethnicity recorded produced reflections on historical backgrounds of persecution and discrimination which had often led participants to take the position that declaring oneself as a Gypsy, Roma, or Traveller would lead to discrimination and poor services. Some strong comments were made by participants about how, as children, they had been told never to declare their ethnicity, for fear that it would only lead to hostility:

“My Mammy said never let on to anyone that you are a Gypsy. Only trouble will follow...”

“I was always told to hide the fact I was a Traveller, and I never understood why till I was much older.”

Such comments clearly indicate that historical oppression and discrimination is still present in the living memory of many communities and, thus, participants were aware of past periods when information about ethnicity was collected for the purpose of control and subjugation.

Fear of discrimination was coupled with **a lack of understanding** for most participants about **why health services would want to collect ethnic data**, other than to differentiate services for certain ethnic groups, services that would be of a lesser quality than all others. One theme that arose in all focus groups was wanting to be **treated like normal human beings**, rather than having to live with the fear that if Gypsy, Roma, or Traveller ethnicity was declared, then they might not be treated as fairly as everybody else. Participants expressed this in ways such as:

“We should just treat all humans as humans...”

“I don’t want the NHS to know more about my culture, because it shouldn’t make any difference to the care you get.”

“I’ve had many unpleasant experiences, so I probably wouldn’t go, and I think other people think the same thing. Well, when we go, we are not treated like normal people, so we’re not going [to health services].”

“Whoever’s the head of the NHS, they need to go and say: “Travellers are no different to anybody else”.”

Participants also commented on the **lack of welcome** they often received in health services, which began with not having their ethnicity listed or respected at the outset of any new contact with health services. It was noted that due to not having their ethnicity listed, participants felt ‘unseen’:

“So, it has to be like, everyone has to be listed, or else they feel like unseen, and they, you know, and it’s a welcome if you’re listed, at least know we exist, yeah, at the start, exactly, yeah.”

No focus group participants could recall a healthcare setting where there had been any posters or children’s toys in the waiting areas that would signify that Gypsies, Roma, and Travellers were a welcome part of that community. One participant suggested the following:

“Seeing some words in the Romany language on forms and posters in the doctor’s surgery would be nice and would make me feel more welcome, even seeing the Gypsy flag somewhere.”

A small number of participants did recognise that if health services and health outcomes for Gypsies, Roma, and Travellers were to improve, then health services would need information about the number of people using their services from different cultural backgrounds and what types of health problems they experience. It was recognised by some participants that without such data, the health outcomes of their communities are unlikely to improve:

“The rationale is that there are certain illnesses and syndromes like mental health, like suicide, in parts of the Traveller communities that aren’t being addressed by the health service. That’s because we don’t talk about it.”

However, such responses were often qualified by **notes of hesitation and fear** as expressed by the following participants:

“I do think that the NHS knowing our ethnicity is good but do worry about having our children taken away. If you go to A&E with a child you have to stay, even if the wait is three days because you’re scared to leave, or they’ll have the social services on you.”

“I agree health should know who we are, but it took me nearly 20 years to get help for my mental health because I was so frightened that social workers would come and take my babies if I said I had depression.”

The need for education of health professionals and associated staff about the nuances and differences between Gypsies, Travellers, and Roma was a consistent theme throughout the groups, some participants offering to carry out such training themselves. Others, however, were perhaps more pessimistic about the benefits any such training might bring, feeling that discrimination was embedded in many professionals, and that it would take more than a training course to change practice at its core. Participants explained this issue:

“We've done awareness raising sessions with health professionals, where we've explored good and bad practice. There's many of these meetings, and yet every time, nothing changes. Every time they ask you the same questions. You tell them the same things over and over and over again and they never take them any further.”

“But the very equal opportunities courses that they go on, and all the diversity, they include sexualities, race, faith, they don't include Gypsy, Roma and Traveller, yeah, and they should do alongside everybody else, yeah, that's what we've pushed for.”

The consequences of a work force that is not culturally aware is that cultural stereotypes promulgated across mainstream mass media, including TV programmes such ‘My Big Fat Gypsy Wedding’ (Channel 4, 2010), could percolate through to health staff and lead to disrespect and cultural misinterpretations as expressed by participants:

“The maternity ward was ok but there was more focus where my husband was and did I suffer domestic abuse than anything else. So, I think they need a bit of education on our tradition and just be more, like, respectful of the person that they've got in with them, rather than thinking about other stuff they've seen on the tele.”

“I had experience with a counsellor who didn't want to speak about my problems. Just wanted to speak about Travellers, like she questioned me about ‘grabbing’... and then there was just me sat in the chair having a full mental breakdown.”

“After you have a baby, the first thing you've got to breastfeed. You've got to breastfeed. 95% Travellers don't want to breastfeed. They're happy with that bottle. That's their way because sometimes your man might watch them, or you've got something else to do and it's what we know. I think it's important that they do find out about the background.”

Even in geographical areas with a higher concentration of a certain ethnic group, participants reported that the local health and social care professionals did not seem to have reached out to these communities in a proactive way, nor made any steps towards understanding their norms and mores. For example, several Gypsy and Traveller focus groups spoke about the regular problems encountered with the tradition that all family members visit ill and dying members of their community in hospital. These **large visitations** by Gypsies and Travellers can be seen by security and health staff as **threatening**, rather than an indication of traditional community practices. Participants explained their experience of visiting hospitals as follows:

“When... [name removed] was ill, all his cousins came to see him, and they [hospital staff] were like, “Oh, my God, I've never seen so many people”. We don't want to try and put the hospital out, or anything like that. That's just us showing the respect by visiting. In our culture, it's the same as if someone's dying, the hospital will be full of people, because that's... a matter of respect to go.”

“I would not want the NHS to know that I was a Gypsy. No, because the kind of comments I heard from some of the nurses, and the way they treated my relative when she was dying was horrendous. “Who do all these Gypsies think they are? And really, I mean, look at them. They're in shock that their sister's dying. They really ought to have been aware of that and take that on board and stop their nonsense and pull themselves together, etc, etc.”

The theme of **cultural sensitivity** in respect of women and medical care ran through all focus groups (note: most of the participants were women). The hope was expressed that if health staff were aware of their ethnicity and had appropriate training, especially training delivered by local Gypsies, Travellers, or Roma, then women might be more sensitively

cared for. Many examples of male health staff having close personal contact with women were mentioned by participants, which created unnecessary stress for participants and their families. While some health services seem able to ensure that female staff treat female community members, much distress is occasioned elsewhere when this does not happen. Participants made the following observations:

“Health people need to know more about what it means to be a Gypsy woman, everything related to being a Gypsy woman. You can’t talk about certain things with men, you just can’t do it. When I’ve had to see a man doctor because he was the specialist, I had no choice. I feel uncomfortable. I find it hard to talk to him about it [my illness], I find it embarrassing trying to talk to a male gynaecologist. It is not culturally allowed to talk to a man about such things. I couldn’t tell me dad it was a man, I lied to his face and felt bad about it. It’s more stress.”

“They think it’s you just being fussy, being awkward because they said to me, “Well, you’ve got a chaperone, and I say: “I know, but I just don’t want to see the man - I try and word it like in a nice way, but I think they just see it’s like “you’re being awkward”.

“We don’t want to have care from a man, imagine letting a man try to lay a hand on our dear old mother. It just would not be allowed to happen.”

There was a general understanding that, particularly in times of financial difficulty, communities could not expect fully customised services, but there were strongly expressed views that their culture should be respected, which could begin by formally recognising their ethnicity. Recognising people’s ethnicity from minority groups will create a positive entry point to the healthcare system. When the recognition of ethnicity is coupled with increased cultural sensitivity by healthcare staff then people from ethnic minorities will feel more open to sharing their ethnicity, leading to more accurate health data. Cultural sensitivity could be enhanced by, wherever possible, making accommodations for issues such as visiting hospitals in large groups and for female patients to be offered a female staff option, even if not immediately available. As participants in general did not think that NHS staff were appropriately informed about their cultural needs, improving health care staff’s cultural awareness would be an important step towards creating a welcoming environment and, in turn, better health data.

Equally, **the need to be listened to** was a recurring theme, a feeling that people were being treated as infantile:

“GPs don’t listen to you and think you’re just a hypochondriac or whatever, or you’re putting it on, and they dismiss you, and they fob you off, you know, in the appointment, without referring you further for scans or whatever else.”

“I can’t read or write that well, but I’m not stupid. I know how to look after my children and give them medicine and ointment.”

Roma focus groups discussed issues regarding not having settled status which made accessing medical care expensive, and their often poor, damp private sector housing conditions were seen to exacerbate certain respiratory diseases. There was a shared view that health professionals not only knew nothing about Roma culture, but they showed no interest in getting to know the community, despite large concentrations of Roma in certain sectors of the cities where the focus groups took place. The **role of interpreters** in mediating Roma access to healthcare was extensively criticised. Examples were given of interpreters chosen from friends and family not being allowed to accompany patients, and of family members being asked to leave consultations for reasons of confidentiality. The result of such practices was that older family members could not explain to their adult children

what the doctor had said due to their limited understanding of English. Official interpreters were not easy to access and there was often concern among Roma that the interpreters were not from the same Roma community, even though they spoke a shared language. Furthermore, certain interpreters were seen as being racist towards Roma, sharing some of the prejudices that are commonplace throughout many Central and Eastern European countries. Experiencing prejudice in health care settings will lead people from ethnic minorities to not declare their true ethnic identity in fear of reduced quality or lack of treatment. This suggests that improving health data on marginalised populations is closely connected to their experience of the health care system.

Roma groups also gave examples of not feeling listened to. The following quote pertains to an older Slovakian Roma woman's hospital stay whom the staff had categorised as Romanian, totally misunderstanding what 'Roma' meant:

“Mum was in hospital, and they didn't realise she was Roma and that there's food she has never eaten, like jacket potatoes, nor the way they serve it, and she went days without eating.”

On a positive note, one Roma daughter gave the following testimony:

“I know some people will not admit they are Roma for fear they will get nothing, but I appreciate the fact that when I do call the doctor, and he doesn't have an interpreter he waits for me and lets me get the language support.”

Preferred modes of communication across all Gypsy, Roma, and Traveller focus groups were those of (mobile) phone calls, and text messages. Problems with receiving post came up in several areas, particularly where Gypsies or Travellers lived on sites where letters may not arrive. Furthermore, older community members often had to wait for a younger member to come along who could read the content of the letter to them. Undelivered and unread letters meant missed appointments, and the sanctions for missing appointments were often that that person had to start again at the bottom of a waiting list. There were examples whereby local health services had recognized the literacy needs of certain communities, and they had adapted their services to be more inclusive, but these were the exception, rather than the rule:

“They [older parents] don't know how to do all that computer stuff, so they're missing more appointments than what they're gaining. If you miss it twice, you're out with a dentist. But they're sending it all through emails and letters, and not every child can read and write. And they sent me a voicemail back in May – I found it in September.”

The rapidly increasing digitalisation of health services access has further alienated members of Gypsy, Roma, and Traveller communities from health services available to them. Although some local services seemed to have accommodated the fact that certain sections, particularly the older members of the communities, have minimal digital literacy. The following quotations indicate challenges with digital literacy and how local services have accommodated community members:

“Where we live now the surgery is perfect, they are all lovely and kind. The receptionist is brilliant, they know we are Gypsies, and they ring us to make an appointment. Can you believe it, they ring us.”

“My dad and mum, they're diabetics, and there's a new system where you've got to go online to order a repeat prescription, and they've made them [health service] aware that they can't do that because they have no internet. They don't even use a debit card, right? So, they're that old school, but I haven't had an issue, and they've been very good with me.”

Nevertheless, experiences of exclusion brought about by a failure to adopt digital systems were more common and led to distress and non-treatment. Participants reported that they gave up trying to get through appointment and other access systems, such as for vaccinations:

“I’ve gone up, and I’ve actually out with them. I’ve said, “Is it because I’m a Romany Gypsy, why I’ve got to stand here waiting like this? Is that what the problem is?” I’ve started asking other people like, “What time was your appointment? And they told me it’s been a lot later than what my appointment was, and they’re still going before you.”

“I took my mom into the doctor’s surgery, and it always seems to be the person that answers the phone for the appointments that I struggle with. And I said, like, Can I get a form to temporary fill it in? I said, because we’re near for a while and they need their repeat prescriptions and whatever. So, she gave me the form, and she got down behind the table and said, “It’s one of them Gypsies off of the site”.”

“The problem is not how they care about us, because when we get appointment, we receive really good health. The lady [Receptionist] say, “I don’t understand you. Please, pardon I can’t understand. What do you mean?” Actually, they always do this to put you down. My English is not perfect, but people, individuals, can be discrimination, yes.”

There was a **lack of understanding** amongst communities themselves about what type of health issues might be prevalent amongst their kin, and beliefs were largely anecdotal regarding which communities might have a propensity to certain diseases or disabilities. The lack of data has always been seen as the reason why there is limited information about the real health needs of Gypsies, Roma, and Travellers. However, so long as Gypsies, Roma, and Travellers do not self-declare their ethnicity, their health needs will remain hidden, rather than profiled and acted upon. Whilst being able to self-identify by having the correct ethnic category listed does not necessarily lead to an improved culturally-aware care experience and, thus, the next step should be ensuring that health care staff responses to certain ethnic categories are not prejudiced. With improved care experience, people will be more likely to declare their ethnicity, which, in turn, will lead to improved data on marginalised populations’ health needs.

One of the major health issues that was well known, though little spoken about in the focus groups, was that of poor mental health and concern about the high rates of suicide particularly in Gypsy and Traveller communities (Note: concerns with mental health and suicide were also noted in the surveys). Many participants across the focus groups suggested that where local Gypsy, Traveller, and Roma organisations existed, they would very much welcome **closer working relationships** with health services, particularly in the field of education and awareness raising. One focus group reported having benefited from local initiatives whereby health staff had taken it upon themselves to visit communities even when there were not pressing health concerns:

“Our organisation’s boss met the health visitors’ boss and asked if her workers could visit our sites, even if there was no emergencies and that. She said “OK, we’ll do that” and they started in a few weeks.”

A consequence of the above noted initiative was a mutually respectful relationship built with health visitors which led to increased uptake rates of vaccination and other health checks.

Conclusions

The fear of identifying as a Gypsy, Roma, or Traveller is rooted in experiences of historical discrimination, a fear which lives on in the many communities who continue to experience a wide range of marginalisation. Harassment, bullying and abuse may be the main reasons why people from Gypsy, Traveller, and Roma communities do not wish to disclose their ethnic identity.

In terms of declaring their ethnic identity with health services, most participants reported never being asked about their ethnicity and, when asked, their specific culture was often not listed. This omission maybe viewed by community members that 'You are not known here' and, as participants noted during focus group discussions: 'You are not welcome / do not belong here'. Members in every focus group expressed some degree of reluctance to declare their ethnicity, less so with the three Roma groups whose main concerns were:

- 1) the limited availability of appropriate interpreters,
- 2) their own articulations of health needs were not listened to,
- 3) the lack of understanding held by health staff about their cultures.

Points 2 and 3 also held true for the Irish Traveller, Scottish Gypsy Traveller, Welsh Gypsy and English Gypsy focus group participants, but the accumulation of negative experiences with UK health services made it less likely that they would ever declare their ethnicity. If categorisations were more in line with communities' self-declaration, then the numbers disclosing their ethnicity would lead to more data being collected. In turn, such improved data should better reflect the numbers of diverse cultures present in specific localities and enable planning of appropriate levels and type of health service. Most focus group participants understood and supported the rationale for such data to enable health services to be more equitable, competent, and customised to cultural needs.

There is, however, a long way to go before the training and awareness levels of all health personnel will be at such levels that members of Gypsy, Roma, and Traveller communities might be treated equitably and competently, particularly when they do declare their ethnicity transparently. The findings showed very low levels of understanding among community members about the prevalence of health problems within their communities. The corresponding lack of knowledge among health professionals about the health needs of Gypsy, Roma, and Traveller families compounds the reasons why multiple morbidities and early mortality rates continue.

This research project represents an important milestone in that a national health initiative (UPD) has commissioned research to investigate this sensitive topic, which had been recommended in several previous studies. The research teams urge all UK health services to operationalise the template recommend on page 28 of this report to better capture the ethnicity categorisation preferences of the UK's Gypsy, Roma, and Traveller communities. The research has also been constructive in bringing the debate about the potential benefits of ethnicity data collection to the attention of the communities and it is hoped that this topic is now more confidently discussed within those communities.

Recommendations

Key recommendations regarding general improvements to be made to health services across the UK to improve the engagement and experience of members from Gypsy, Roman, and Traveller communities:

- 1) Collect ethnicity data to justify positive social action and enable health service planning. Communicate reasons for collection to community members at the point of request.
- 2) Self-identification is the generally suggested approach to collecting ethnicity data (see also [Desk Review](#)). If an individual is unable to self-identify at the point of entry to the health service, their ethnic identity, along with other demographic information, should be checked with them as soon as it is practicable.
- 3) Build more meaningful connections with trusted local Gypsy, Roma, and Traveller organisations. Community members have trust in their local advocacy organisations, and they would be more likely to attend health education sessions in those settings. Therefore, to better engage with and reach out to community members, working closely with local Gypsy, Roma, and Traveller organisations is essential. Improving culturally informed care may also improve willingness and confidence in declaring ethnicity.
- 4) Shift communication with community members about appointments and other health service-related information from a traditional postal letter-based approach (letters don't get delivered/read in time) to phone/text messages. Most community members are adept at using mobile phones as a core means of communication.
- 5) The gender imbalance in the study reflected traditional community perspectives, with participation significantly leaning towards women. Therefore, health services, charities and organisations wishing to engage Gypsy, Roma, and Traveller communities should ensure they plan and carry out health improvements with the active involvement of women from the communities.

The recommended ethnic categories based on data collected from target communities and feedback sought from the AG are:

- English Gypsy/Romany
- Irish Traveller
- Scottish Gypsy Traveller
- Welsh Gypsy/Romany
- Roma
- English Traveller

Whilst the categories were supported by all members of the AG, a discussion between representatives of big data organisations and community members indicated a difference in view between the two stakeholder groups. Big data representatives highlighted that the further division (as per the recommended categories by the findings of this study) of Gypsy, Roma, and Traveller groupings could lead to communities in those categories being lost in big datasets that are collected through national censuses and regional surveys, and therefore sometimes granularity in ethnicity categories can in fact be less helpful. On the other hand, community members wanted their ethnic identity clearly distinguished and represented in national and regional statistics to have their presence recognised, which would require adopting greater granularity in ethnicity categories. The recommendation emerging from that discussion was to have Gypsies and Travellers represented as one group and Roma as a separate one in big datasets as Roma have different backgrounds as

recent migrants from Central and Eastern Europe and tend to face somewhat different challenges across health services. In sum, we would emphasize the importance of keeping communication lines open between policy and analytics organisations, and community members to ensure changes to our data practices are pragmatic but also respectful.

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- Josie O’Driscoll, CEO of GATE Herts – Irish Traveller
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- Rebecca Asher and Emily Jesper-Mir – Partnerships and Engagement Managers in Data for Science and Health Team at Wellcome Trust

Appendices

Appendix 1. Survey questions

1. What is your gender?
 - Man
 - Woman
 - If not listed, please self-identify:
2. How old are you? Please state:
3. What sort of home do you live in? (Please select more than one if applicable.)
 - Bricks and mortar (house/bungalow/flat)
 - Caravan/Chalet on a site
 - Travel all year or part of the year round in a trailer, caravan or motorhome
 - If not listed, please describe your home:
4. In which country were you born?
 - England
 - Wales
 - Scotland
 - Northern Ireland
 - Republic of Ireland
 - If not listed, please state the country you were born in:
5. If you were not born in the United Kingdom, when did you first move here?
 - Please provide the year of your arrival:
6. What country do you mainly live in now? (Please select more than one if applicable.)
 - England
 - Wales
 - Scotland
 - Northern Ireland
 - Republic of Ireland
 - If not listed, please specify:
7. What is your religion?
 - Buddhist
 - Jewish
 - Hindu
 - Muslim
 - Protestant
 - Roman Catholic
 - Other Christian denomination
 - Sikh
 - No religion
 - If not listed, please self-identify.
8. What language or languages did you grow up with?

- Please list the language(s):
9. If you grew up with more than one language, what is your main language?
- Please state your main language:
10. How comfortable do you feel talking to a health professional in English?
- Very comfortable
 - Comfortable
 - Not very comfortable
 - Not at all comfortable
11. Which of the following describes what you have been doing in the last 5 years?
- Full time paid employee
 - Part time paid employee
 - Self-employed
 - Retired
 - Looking after home and family
 - Long term sick/disabled
 - Studying
 - Looking for/between jobs
 - Serving in the armed forces
 - Unemployed
 - If not listed, please describe.
12. Please describe your highest level of education.
- Apprenticeship
 - GCSE or equivalent
 - A level or equivalent
 - NVQ or equivalent
 - Graduate education
 - Postgraduate education
 - Professional qualification
 - No formal qualifications
 - Other qualification – please describe.
13. How do you describe your ethnic group (your cultural background and experience)?
(Please select more than one if applicable.)
- English, Welsh, Scottish, Northern Irish or British
 - Irish
 - Romany
 - Roma
 - English Gypsy
 - Welsh Gypsy
 - Scottish Gypsy Traveller
 - Gypsy or Irish Traveller
 - Showman
 - Please describe your preferred ethnic group if it is not listed.

14. How would you describe your national identity (your sense of belonging to one or more nations)? (Please select more than one if applicable.)

- British
- English
- Cornish
- Scottish
- Welsh
- Irish
- Northern Irish
- European
- If not listed, please self-identify.

15. How often do you use the NHS/GP/health visitor?

- Never
- Hardly ever
- Sometimes
- Frequently
- Always

16. If you never use the NHS, please explain why.

17. How has been your experience when using the NHS?

- Very good
- Good
- Fair
- Bad
- Very bad

Can you explain why you chose your answer?

18. During your visit to the NHS, are you asked about your ethnicity?

- Never
- Hardly ever
- Sometimes
- Often
- Always

19. If you were asked about your ethnicity by the NHS, was your preferred ethnicity listed?

- Yes
- No

20. If your answered 'No' to question 19 then what description would like to have given?

- English, Welsh, Scottish, Northern Irish or British
- Irish
- Romany
- Roma
- English Gypsy
- Welsh Gypsy

- Scottish Gypsy Traveller
 - Gypsy or Irish Traveller
 - Showman
 - Please describe your preferred ethnic group if it is not listed.
21. If you did not give your ethnicity when visiting the NHS, please explain why?
22. Do you think it is relevant for the NHS to have accurate information about patients' ethnic identity?
- Very important
 - Important
 - Somewhat important
 - Not important
 - Not very important
 - Don't know
23. Do you think that people who work for the NHS are appropriately informed about your cultural needs/background?
- Very well informed
 - Well informed
 - Adequately informed
 - Not well informed
 - Poorly informed
 - Don't know
24. What cultural understanding do you expect NHS staff members to already have about your community?
Please state.
25. Should more research be carried out regarding how to provide effective health care for your community?
- Yes
 - No

If 'yes', what areas of health research do you think should be carried out?

Appendix 2. Focus group interview questions

1. When was the last time you/family members used an NHS service?
2. What is your experience of using NHS services?
3. Have you ever been asked about your ethnicity during an NHS visit?
4. If so, what was your experience of having to report your ethnicity?
5. How did you have to report your ethnicity: verbal, written, ticking the right box?
6. Do you think it is important for health care providers to have accurate ethnic data? If yes/no, why?
7. Do you think that NHS staff members are appropriately informed about your cultural needs/background?
8. If not, please share what you'd like better awareness of and your ideas for raising cultural awareness in the NHS.
9. Do you, your family or community members experience any difficulties with spoken and written English?
10. If so, what do you think is the best way to improve the ways NHS services communicate with you?
11. How do you feel about ethnicity data recording/monitoring in the NHS? (infographic on next page to support questions 11/12)
12. What do you think is the best way to improve ethnic data monitoring in the NHS for your community?
13. Finally, in your view, how the experience of reporting your ethnicity in health care settings could be improved?