

## No room at the inn: How easy is it for nomadic Gypsies and Travellers to access primary care?

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The NHS England Patient Registration Standard Operating Principles for Primary Medical Care says, “When applying to become a patient there is no regulatory requirement to prove identity, address, immigration status or the provision of an NHS number in order to register”<sup>1</sup>. However, we regularly hear from service users from Gypsy and Traveller communities that have been refused registration at a doctor’s surgery because they have no proof of identification or because they have no address. To ascertain the extent to which this is an issue in general practices (GPs) in England, we mystery shopped 50 doctor’s surgeries in December 2018 and January 2019.

### Method

Our mystery shoppers phoned 50 general practices posing as someone who had recently moved into the area and who wanted to come into the practice to register to become a patient. The mystery shopper said they hadn’t been to a GP in a while but had a “woman’s problem” that they thought needed to be looked at. The mystery shopper said that they didn’t have a fixed address because they were from the Traveller community and were travelling, and also said they had no proof of identity.

### Key Findings

- 24 out of 50 GP practices we contacted in England would not register our mystery shopper.
- Despite this, every GP practice was rated ‘good’ or ‘outstanding’ by the Care Quality Commission for their work with ‘People whose circumstances may make them vulnerable’.
- GP practices were significantly more likely to refuse to register our mystery shopper in urban areas compared to rural areas.
- GP practices were significantly more likely to refuse to register our mystery shopper in areas where there are large Gypsy and Traveller populations compared to where there are not.

### Introduction

Gypsy and Traveller communities are known to face some of the most severe health inequalities and poor life outcomes amongst the United Kingdom population, even when compared with other groups experiencing exclusion, and with other ethnic minorities<sup>2</sup>. Gypsies and Travellers are estimated to have life expectancies of between ten and 25 years shorter than the general population<sup>34</sup> and experience six less Quality Adjusted Life Years (that is, years spent in good health)

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<sup>1</sup> NHS England (2015) ‘Patient Registration Standard Operating Principles for Primary Medical Care (General Practice)’. Last accessed 11 Mar 2019. Available at: <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2018/01/patient-registrations.pdf>

<sup>2</sup> Parry et al (2007) ‘Health status of Gypsies and Travellers in England’. *J Epidemiol Community Health*. 2007 Mar; 61(3): 198–204.

<sup>3</sup> Equality and Human Rights Commission (2009) ‘Gypsies and Travellers: Simple Solutions for Living Together’. Last accessed 11 Mar 2019. Available at: <https://www.equalityhumanrights.com/en/gypsies-and-travellers-simple-solutions-living-together>

<sup>4</sup> Baker, M. (2005) Gypsies and Travellers: Leeds Baseline Census. Last accessed 11 Mar 2019. Available at: <https://leedsgate.co.uk/sites/default/files/media/BaselineCensus.pdf>

before life expectancy is taken into account<sup>5</sup>. Data from the 2011 Census found that in England and Wales, Gypsies and Travellers had the lowest proportion of people rating their general health as 'good' or 'very good' at 70 per cent compared to 81 per cent overall<sup>6</sup>.

There are around 300,000 Gypsies and Travellers in the UK<sup>7</sup>, of which around a quarter live in a caravan or other mobile or temporary structure<sup>8</sup>. Of these, the 3000 Gypsy and Traveller families (roughly 10,000 people) who live on unauthorised encampments<sup>9</sup>, with no fixed address, are at the greatest risk of being refused healthcare. Further to this, many of the 20,000 Gypsy and Traveller families<sup>10</sup> (roughly 70,000 people) who live on authorised sites will also travel periodically and will experience the same barriers to accessing primary care while travelling.

We know from our casework that Gypsy and Traveller communities are often less likely to be able to provide photo identification than members of the general population. This puts Gypsy and Traveller communities at greater risk of being refused healthcare if the receptionist says patients need identification to register.

## **Background to the issue**

*"I only persisted with attempting to register because I knew I actually had cancer. It has turned out to be a stage 3 cancer. There were three tumours and five affected lymph nodes. Despite the fact that I knew my rights, provided information on registering at a GP's address and articulated my case, I had to compromise my confidentiality on two occasions to access belated care for an aggressive, life threatening disease which could have been caught years earlier."*

Kit

Being refused registration at GP practices has been a longstanding problem for Gypsy and Traveller communities. Lack of progress in this area has been a source of international scrutiny, in fact, the UN Committee on the Convention on the Elimination of All Forms of Racial Discrimination<sup>11</sup>, the UN

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<sup>5</sup> Parry et al (2007) 'Health status of Gypsies and Travellers in England'. J Epidemiol Community Health. 2007 Mar; 61(3): 198–204.

<sup>6</sup> Office for National Statistics (2014) '2011 Census analysis: What does the 2011 Census tell us about the characteristics of Gypsy or Irish travellers in England and Wales?' Last accessed 11 Mar 2019. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/whatdoesthe2011censustellusaboutthecharacteristicsofgypsyoririshtravellersinenglandandwales/2014-01-21>

<sup>7</sup> Council of Europe (n.d.) 'Roma and Travellers Team'. Last accessed 11 Mar 2019. Available at: <https://www.coe.int/en/web/portal/roma/>

<sup>8</sup> See footnote 6

<sup>9</sup> MHCLG (2018) 'Count of Traveller Caravans, July 2018 England'. Last accessed 11 Mar 2019. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/756234/TCC\\_Nov18\\_Stats\\_Release.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/756234/TCC_Nov18_Stats_Release.pdf)

<sup>10</sup> Ibid

<sup>11</sup> UN Committee on the Elimination of Racial Discrimination (2016) 'Concluding observations on the combined twenty-first to twenty-third periodic reports of the United Kingdom of Great Britain and Northern Ireland' Last accessed 11 Mar 2019. Available at: <https://undocs.org/en/CERD/C/GBR/CO/21-23>

Committee on Economic, Social and Cultural Rights<sup>12</sup> and the UN Committee on the Rights of the Child<sup>13</sup> have specifically called on the UK government to address this issue.

*“I was on the road in Surrey and went to a GP with a really bad infection. I wasn’t feeling right in my head or in my body. The surgery said they wouldn’t register me with a care of address in another area because I needed blood tests and there was no use in sending the results somewhere else. They were very apologetic about it. A neighbour near where I was parked said I could use their address, but I don’t know what I would have done if they hadn’t let me – I wouldn’t have been able to receive the long term treatment I needed.”*

Colin

In our casework, the main reasons we hear that Gypsies and Travellers are refused registration at GP practices is because they are not able to provide an address or they have no proof of identification. However, this is not a problem unique to Gypsies and Travellers; other groups also experience similar problems. These include asylum seekers and refugees, people in contact with the criminal justice system, homeless people, vulnerable migrants and people fleeing from domestic violence. Even though it is against NHS England policy, GP practices often refuse to register people from these groups if they cannot provide an address, identification, an NHS number, a utility bill or proof of immigration status. These groups are often at higher risk of poor health, but experience the greatest inequalities in access to healthcare.

*“I went to a doctor in Stroud a few years ago with 2 cracked ribs, coughing up blood. I had proof of address and all the relevant documents but hadn’t previously been registered at a surgery in the UK before. They said they didn’t believe that I hadn’t had a GP before and wouldn’t register me. I went home and Googled for a different GP nearby and they registered me, no problem. I was surprised that within the NHS they wouldn’t see me without filling all the forms, even when I was clearly in pain. I was upset that people can put form filling in front of someone’s wellbeing.”*

Glen

We know from our casework and outreach work that past experiences of being refused healthcare has a long term impact on how people experience health services. Many Gypsies and Travellers fear discrimination or lack of understanding of their culture from health professionals and as a result may find it hard to build trust with health professionals. Being refused healthcare in the past or knowing

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<sup>12</sup> UN Committee on Economic, Social and Cultural Rights (2016) ‘Concluding observations on the sixth periodic report of the United Kingdom of Great Britain and Northern Ireland’. Last accessed 11 Mar 2019. Available at: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=4sIQ6QSmIBEDzFEovLCuW3XRinAE8KCBFoqOHNz%2fvuCC%2bTxEKA18bzE0UtfQhJkxxOSGuoMUxHGypYLjNFkwxnMR6GmqogLJF8BzscMe9zpGfTXBkZ4pEaigi44xqiL>

<sup>13</sup> UN Committee on the Rights of the Child (2016) ‘Concluding observations on the fifth periodic report of the United Kingdom of Great Britain and Northern Ireland’. Last accessed 11 Mar 2019. Available at: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhskHOj6VpDS%2f%2fJqg2Jxb9gncnUyUgbnuttBweOlylfyYPkBbwffitW2JurgBRuMMxZqnGgerUdpjxij3uZ0bjQBOLNTNvQ9fUIEOvA5LtW0GL>

that many Gypsies and Travellers are being refused healthcare because of travelling reinforces these fears and feelings of mistrust for all Gypsies and Travellers.

*“It makes you feel like you’re alien from everyone else. Just because of who you are, you don’t get the same treatment as everyone else. You know full well that if you were someone else, if you had this document or that, you’d be able to get the help you need, but because you don’t you’re left with no help at all.”*

Danielle

Over the years, a number of initiatives have taken place to improve patients’ awareness of their rights around access to primary care. In London, Groundswell together with Healthy London Partnership have produced a ‘Right to Healthcare’ card<sup>14</sup>. In addition, NHS England released a leaflet for Gypsy, Roma and Traveller communities nationally called ‘Ethnic Gypsy, Roma and Traveller communities: How to register with a doctor’<sup>15</sup>. However, the leaflet uses complex language so is inaccessible to many of our service users, 45% of whom have low or no literacy. More importantly, we have supported individuals who knew their rights around registering, have high levels of literacy, and who presented a copy of the leaflet to a receptionist and were still refused registration. In terms of face to face or telephone support, organisations such as Healthwatch and our own organisation, Friends Families and Travellers, provide support and advocacy to people who have been refused registration at GP practices.

Whilst these are useful tools which can overcome barriers to access to healthcare on an individual level, members of communities who are most likely to need to use them are often unaware of their existence. We also know that they do not always work, or sometimes work but create a time delay before an individual is able to access healthcare.

Additionally, by putting the onus on an individual to advocate for their right to access healthcare, this may make people less likely to want to attend the GP, can be difficult for people who are feeling unwell or who are experiencing poor mental health and can reinforce feelings of being unwelcome and expectations of discrimination. For this reason, it is vital that we focus our efforts on creating real systemic change in this area.

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<sup>14</sup> Groundswell (n.d.) ‘My Right to Healthcare Cards’. Last accessed 11 Mar 2019. Available at: <http://groundswell.org.uk/what-we-do/health/my-right-to-healthcare-cards/>

<sup>15</sup> NHS England (n.d.) ‘Ethnic Gypsy, Roma and Traveller Communities: How to register with a doctor’. Last accessed 11 Mar 2019. Available at: <https://assets.nhs.uk/prod/documents/how-to-register-with-a-gp-gypsy-traveller-roma-communities.pdf>

## Results of our research

### Registrations refused

We found that of the 50 GP practices we mystery shopped, 24 would not register our mystery shopper (neither as a permanent patient nor as a temporary patient). Of these:

- 17 GP practices said they could not register people without proof of identification
- 12 GP practices said they could not register people without an address
- 1 GP practice said they could only register people online
- 2 GP practices never picked up the phone, despite multiple calls on different days

### Analysis of results

We mystery shopped GP practices in urban areas, rural areas, areas where we know there are large Gypsy and Traveller populations and areas where we know there aren't many Gypsies and Travellers and found that GP practices were significantly more likely to refuse to register our mystery shopper in urban areas and in areas where there are large Gypsy and Traveller populations.

	Number of GP practices who refused to register our mystery shopper	Total number of GP practices we mystery shopped
Urban areas	9	12
Rural areas	4	14
Areas with large Gypsy and Traveller populations	8	12
Areas with small Gypsy and Traveller populations	3	12
Total	24	50

The finding that GP practices in urban areas were more likely to refuse to register our mystery shopper could be because of pressures on GP practices in urban areas mean that some groups who are vulnerable because of their circumstances are more likely to be squeezed out. It also may be reflective of the relative strengths within rural GP practices who may be more likely to take a more personalised and proactive approach<sup>1617</sup>.

The finding that GP practices in areas with large Gypsy and Traveller populations were more likely to refuse to register our mystery shopper was alarming. We initially had thought that areas with large Gypsy and Traveller populations would be more aware of their responsibilities to these communities and therefore be more likely to be compliant with NHS England guidelines. We are concerned that this finding might be reflective of high levels of discrimination in areas where many Gypsies and

<sup>16</sup> Toby Tattersall (2012) 'Rural medicine—what's it really like?' BMJ 2012;344:e1149. Last accessed 11 Mar 2019. Available at: <https://www.bmj.com/content/344/bmj.e1149>

<sup>17</sup> Pohontsch, N. et al (2018) 'General practitioners' perception of being a doctor in urban vs. rural regions in Germany - A focus group study' Fam Pract. 2018 Apr; 35(2): 209–215. Last accessed 11 Mar 2019. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5892171/>

Travellers live, in particular, in places where there are higher levels of unauthorised encampments. This will need to be examined further.

However, we also know from our casework that some GP practices have reported feeling overwhelmed when providing care to Gypsy and Traveller families or individuals. This may be because families or individuals haven't accessed healthcare in some time so may present to GP practices with a number of issues, it may be because Gypsies and Travellers sometimes tend to arrive in larger groups or it may be because Gypsy and Traveller people are more likely to be experiencing poor health and co-morbidities. It would be useful to explore this further.

### **Analysis of Care Quality Commission Ratings**

The Care Quality Commission (CQC) is responsible for regulating GP practices and does this through information gathered at regular inspections and by using data provided by the Quality and Outcomes Framework, GP Patient Survey, NHS Business Services Authority and Public Health England. Notably, this information does not disaggregate Gypsy and Traveller populations by ethnicity and people can only participate in the GP Patient Survey if they have a postal address and if they are registered at a GP surgery.

The invisibility of Gypsies and Travellers, particularly those with no fixed address, in national patient satisfaction datasets for primary care means that under current arrangements it is crucial that the CQC pick up on issues around access and patient satisfaction for these communities during inspections. Information on a GP practice's performance in this area should be found in the section of the inspection report titled, '*Care of people whose circumstances may make them vulnerable*'. However, we reviewed the CQC Inspection Reports of the 24 GP practices who would not register our mystery shopper and found that:

- 2 GP Practices were rated 'Outstanding' in their care of people whose circumstances may make them vulnerable;
- 20 GP Practices were rated 'Good' in their care of people whose circumstances may make them vulnerable;
- 2 GP Practices had not yet been inspected by the CQC; and
- Not one GP Practice was rated as 'Requires Improvement' or 'Inadequate' in their care of people whose circumstances may make them vulnerable.

When we examined the CQC inspection reports, we found that there was a real variability to what inspectors considered in the vulnerable populations section of the report. It was evident that the majority of GP practices were aiming to make their services inclusive for one or more groups of people whose circumstances made them vulnerable, but there didn't appear to be a clear or consistent understanding between inspectors and within GP practices on what groups are considered vulnerable, what actions should be taken to support these groups and how to meaningfully evidence that those actions had been taken.

Inspectors used the '*People whose circumstances may make them vulnerable*' section of the CQC GP Practice report to highlight:

- multi-disciplinary working in the case management of vulnerable patients;
- signposting to various support groups and voluntary organisations;
- staff knowledge of safeguarding procedures;
- that practices offered double appointments to people with learning disabilities;
- practices' support for patients receiving end of life care;
- practices' support for housebound patients;
- how practices supported accessibility to patients with hearing impairments;
- protocols to ensure inclusivity for carers;
- the range of languages spoken by the GP and non-clinical staff;
- the system for vaccinating patients with an underlying medical condition;
- that patients were offered alcohol screening during health checks;
- support offered to children in care;
- that a member of staff was identified as a domestic violence champion; and
- support for asylum seekers.

However, most inspectors would usually cover only four or five of these points and never covered all of them.

In terms of inclusion of Gypsy and Traveller communities in inspection reports, many GP practices reported to inspectors that they held a register of patients living in vulnerable circumstances including homeless people, Travellers and those with a learning disability. However, even when GP practices had this in place, this did not seem to make any difference to the outcome for our mystery shopper when trying to access healthcare.

Notably, one CQC inspection report said, *"The practice had no travellers (sic) or homeless people on their patient list at the time of our inspection but explained they would register and accept people from these groups as temporary or permanent patients as needed."* The same practice said they would not register our mystery shopper unless they provided a passport or a driving licence as well as a proof of local address. It is clear that CQC inspectors, in the absence of any evidence which proves otherwise, have little option but to rate GP practices as 'Good' or 'Outstanding'.

Also of note, despite the fact that Romany Gypsies and Irish Travellers are legally recognised as ethnic groups and protected by the Equality Act 2010, not one report that we reviewed by the Care Quality Commission correctly capitalised the 'T' at the beginning of Traveller, as would be the case for other ethnic groups.

The fact that the Care Quality Commission has not successfully been able to identify even one GP practice which refused to register our mystery shopper makes it clear that regulation of GP practices in relation to access to primary care for people with no address or no identification urgently requires a new and more effective approach.



## **Solutions**

Ten years have now passed since the publication of NHS England's '[Primary care service framework: Gypsy & Traveller communities](#)' which highlighted significant issues around access to primary care for Gypsy and Traveller communities and outlined steps to address these. Sadly, we have seen little or no measurable improvement in this area in the past decade.

Given the severity of the issue and the wide range of stakeholders from across the health and social care system who play a part in this, we would like to see a taskforce set up to lead and drive forward this work. The taskforce should include representatives from NHS England, the Care Quality Commission, the Royal College of General Practitioners, Healthwatch, members of the voluntary sector, people with lived experience of being refused registration at GP practices and representatives of GP practices who have shown leadership in this area. The taskforce should take forward the following recommendations:

### **Recommendation 1**

NHS England should develop a clear understanding of why GP practices may be reluctant to register certain patients and ensure that appropriate incentives and deterrents are in place to address this. This might be through funding mechanisms linked to the Quality and Outcomes Framework and/or the Carr Hill Formula and should be explicit in the GP Contract.

### **Recommendation 2**

NHS England should develop a mandatory national Inclusion Health training and communication strategy to ensure all GP receptionists and practice managers are aware of their responsibilities to patients with no fixed address, no identification or no proof of immigration status. This should both outline responsibilities on registering patients and include guidance on communication and stigmatisation.

### **Recommendation 3**

NHS England should create a specific forum to facilitate listening to the patient experience of members of Inclusion Health groups across each stream of its work. Where the experiences shared in these groups are not being picked up by routine data collection or regulatory work, specific pieces of research should be commissioned to establish an evidence base for action.

### **Recommendation 4**

The Care Quality Commission should redesign the 'People whose circumstances may make them vulnerable' section of the inspection report. Together with GPs, inspectors, voluntary sector organisations and patient experts, they should develop specific and measurable indicators to be regulated, name the specific groups covered in this section and specific actions GP practices should be taking to achieve a 'good' or 'outstanding' rating for all 'vulnerable' communities.



### **Recommendation 5**

The Care Quality Commission should launch and extensively promote a website which members of the public and of the voluntary sector can use to report when a GP practice turns someone away. Data recorded through this should be considered by inspectors and fed into ratings.

### **Recommendation 6**

The Equality and Human Rights Commission should take legal action where there is evidence that a GP practice has been aware of their responsibilities and still refused to register a member of the Romany Gypsy, Irish Traveller or Roma communities.

### **Recommendation 7**

In light of the restrictions which prevent the Care Quality Commission from mystery shopping GP practices, the Department of Health and Social Care should commission independent organisations to mystery shop GP practices assessing issues around access either at a national scale or at CCG level. Findings should be made public.

### ***Thank you***

*Thank you to Martha Ostick who supported us with carrying out the mystery shopping exercise and to our national casework and outreach teams for supporting us in identifying cases where people had been refused access to healthcare.*

### **About us**

Friends, Families and Travellers is a leading national charity that works on behalf of all Gypsies, Roma and Travellers regardless of ethnicity, culture or background.

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