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# **Locked out: A snapshot of access to General Practice for nomadic communities during the COVID-19 pandemic**

**Report compiled by:  
Mattey Mitchell  
Josie Garrett**

## **Locked out: A snapshot of access to General Practice for nomadic communities during the COVID-19 pandemic**

Romany and Traveller people in England face longstanding barriers to primary healthcare services<sup>1</sup>. Between 2018 and 2019, we mystery shopped 50 General Practices (GPs) in England and found that, despite no regulatory requirement to provide proof of address or identification in order to register, nearly half of all GP practices we contacted refused registration on this basis.<sup>2</sup> Within the context of COVID-19, we have heard from our casework team that a shift towards digital-first processes for registration has resulted in additional barriers to care. To gain an updated understanding of access to primary healthcare in this context, we mystery shopped 100 GPs in England between March and April 2021.

### **Method**

Our mystery shopper contacted 100 GP practices to request to register as a patient. The mystery shopper said that they are Romany and that they had no fixed address as they were travelling. We know from our casework that people from Romany and Traveller communities are often less likely to be able to provide photo identification than members of the general population, and so our mystery shopper stated that they have no proof of identity. We also know that the failure of services to offer communication options for patients with low levels of literacy or experiencing digital exclusion can present major barriers to care for some patients from Romany and Traveller communities. Where practices would otherwise register our caller, our mystery shopper therefore requested whether there were alternative options to online registration, and if support could be provided to complete registration forms.

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<sup>1</sup> <https://www.gypsy-traveller.org/wp-content/uploads/2019/03/No-room-at-the-inn-findings-from-mystery-shopping-GP-practices.pdf>

<sup>2</sup> <https://www.gypsy-traveller.org/wp-content/uploads/2019/03/No-room-at-the-inn-findings-from-mystery-shopping-GP-practices.pdf>

## Key Findings

Out of 100 GP surgeries contacted:

- 74 GP surgeries broke NHS England guidance and refused to register our mystery shopper because they were unable to provide proof of identity, proof of fixed address, register online or another reason.
- 17 GP surgeries did not answer the phone despite receiving phone calls on three different dates and times from our mystery shopper.
- 2 GP surgeries who otherwise agreed to register our mystery shopper refused to give help with form filling.

This means that for patients experiencing multiple disadvantage, with no address, no identification and low or no literacy leading to digital exclusion, only 6 out of the 100 GP surgeries would have allowed them to register. This means that inequalities in registration for people living nomadically has significantly worsened since our last report in 2019.

## Background

Romany and Traveller communities are known to face some of the starkest health inequalities in the UK, with estimated life expectancies between 10 and 25 years shorter than the general population and six less Quality Adjusted Life Years (that is, years spent in good health) before life expectancy is taken into account.<sup>34</sup> Romany and Traveller communities also experience a higher prevalence of long-term illness<sup>5</sup>, multimorbidity and premature frailty.<sup>6</sup> The average health of a Romany or Traveller person in their 60s, is comparable to an average White British person in their 80s.<sup>7</sup>

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<sup>3</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>4</sup> Parry et al (2007) 'Health status of Gypsies and Travellers in England'. *J Epidemiol Community Health*. 2007 Mar; 61(3): 198–204.

<sup>5</sup> Ibid.

<sup>6</sup> [https://www.gypsy-traveller.org/wp-content/uploads/2020/10/health\\_ineq\\_final.pdf](https://www.gypsy-traveller.org/wp-content/uploads/2020/10/health_ineq_final.pdf)

<sup>7</sup> [https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(20\)30287-5/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(20)30287-5/fulltext)

There are around 300,000 Romany and Traveller people in the UK<sup>8</sup>, of which around a quarter live in a caravan or other mobile or temporary structure.<sup>9</sup> Of these, the 3000 Romany and Traveller families (roughly 10,000 people) who live on roadside camps<sup>10</sup>, with no fixed address, are at the greatest risk of being refused healthcare. Further to this, many of the 20,000 Romany and Traveller families<sup>11</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.

It is difficult to ascertain the population of Liveaboard Boaters in the UK. Information from the Royal Boat Owners Association highlights that at least 15,000 people are thought to live afloat in Great Britain, however, the National Bargee Travellers Association estimate that over 50,000 or more people are living on boats.<sup>1213</sup>

## Introduction

Wrongful registration refusal is a longstanding issue faced by Romany and Traveller people when accessing primary care services.<sup>14</sup> This issue has garnered international scrutiny, and the Women and Equalities Committee have previously called on healthcare services to address this.<sup>1516</sup>

In 2019, we published the report 'No Room at the Inn: how easy is it for nomadic Gypsies and Travellers to access primary care?' after mystery shopping 50 general practices in England.<sup>17</sup> Although there is no regulatory requirement to provide ID or a fixed address, 24 of 50 GPs would not register our mystery shopper on this basis.

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<sup>8</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/>

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<https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/datasets/2011censusanalysiswhatdoesthe2011censustellusaboutthecharacteristicsofgypsyoririshtravellersinenglandandwales>

<sup>10</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>11</sup> Ibid.

<sup>12</sup> <https://www.rboa.org.uk/q-a/>

<sup>13</sup> Figure suggested by NBTA through email to Friends Families and Travellers

<sup>14</sup> <https://www.gypsy-traveller.org/wp-content/uploads/2019/03/No-room-at-the-inn-findings-from-mystery-shopping-GP-practices.pdf>

<sup>15</sup> Ibid.

<sup>16</sup> <https://publications.parliament.uk/pa/cm201719/cmselect/cmwomeq/360/full-report.html#heading-10>

<sup>17</sup> <https://www.gypsy-traveller.org/wp-content/uploads/2019/03/No-room-at-the-inn-findings-from-mystery-shopping-GP-practices.pdf>

Despite this, every GP practice was rated 'good' or 'outstanding' by the Care Quality Commission (CQC) for their work with, 'people whose circumstances may make them vulnerable' which is the section of the CQC inspection report which should ordinarily pick up these issues.<sup>18</sup>

The issue of refused registration as a result of factors such as no fixed address or proof of identity is also experienced among other groups experiencing stark health inequalities, including people experiencing homelessness, and migrants in vulnerable circumstances. In keeping with this, in a report released in 2018, Doctors of the World found that out of a total of 2189 attempts to register patients, patient registration was refused on 419 occasions.<sup>19</sup>

Within the context of COVID-19, we have heard from our casework team that the radical shift towards digital-first service delivery has resulted in additional barriers to primary healthcare for those experiencing digital exclusion. We set out to build a picture of access to registration during the pandemic for people living nomadically.

## Results of our research

### Overall accessibility of GP registration

In order to identify GP practices, we randomly selected GP surgeries from across England from the NHS Digital "epracur" database of all GP practices nationally, removing surgeries from the list which were no longer in operation.<sup>20</sup>

Out of 100 GP surgeries contacted:

- 39 GP surgeries refused registration to patients who were unable to provide both proof of identity and proof of fixed address
- 13 GP surgeries refused registration to patients who were unable to provide proof of identity
- 8 GP surgeries refused registration to patients who were unable to provide proof of address<sup>21</sup>

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<sup>18</sup> Ibid.

<sup>19</sup> <https://www.doctorsoftheworld.org.uk/wp-content/uploads/2019/08/Registration-Refused-final.pdf>

<sup>20</sup> <https://digital.nhs.uk/services/organisation-data-service/data-downloads/gp-and-gp-practice-related-data>

<sup>21</sup> One surgery stated that patients with no fixed address would need to speak to the local authority, who could allocate a GP practice for them, which is not in line with NHS England and Improvement policy.

- 17 GP surgeries did not answer the phone despite receiving phone calls on three different dates and times from our mystery shopper
- 4 GP surgeries refused to register our mystery shopper for other reasons
- 11 of the 19 GP surgeries who would otherwise register our mystery shopper refused to register patients who were unable to use their online registration facilities
- 2 of the 8 GP surgeries who did say that our mystery shopper could be registered there refused to support with filling out forms when the mystery shopper disclosed that they had low literacy and would like support

This means that for patients experiencing multiple disadvantage, with no address, no identification and low or no literacy leading to digital exclusion, only 6 out of the 100 GP surgeries would have allowed them to register.

Our research shows that inequalities in registration for people living nomadically has worsened since our last report in 2019. While some positive actions have been taken, for example, the launch of primary care access cards, calls for General Practice to ensure accessibility of registration during the COVID-19 pandemic, the development of an Inclusion Health Tool for Primary Care Networks and more, ultimately, these have not been significant enough to change the outcomes of longstanding issues with refused registration.

Whilst we acknowledge that these occur against a backdrop of a primary care system under immense amounts of pressure and one which has quickly adopted digital approaches to keep people safe from the spread of COVID-19, it is unacceptable, inhumane and in breach of nomadic people's human rights that such barriers to registration exist and continue to worsen.

### **Registration refusal as a result of no proof of identification or proof of fixed address**

The NHS England Patient Registration Standard Operating Principles for Primary Medical Care is clear that, "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>22</sup> The Guidance and Standard Operating Procedures for General Practice in the Context of COVID-19 also states that -

*“Practices should continue to register new patients where capacity allows, prioritising those with no fixed address, asylum seekers, refugees and people leaving custody. Practices may only refuse registration if they have reasonable grounds to refuse services to patients.”*<sup>23</sup>

Our findings demonstrate that, despite this guidance, many GP practices are not prioritising patients with no fixed address, and are continuing to refuse registration to nomadic patients.

The gap between primary care policy and practice in terms of registration for those with no fixed address or ID has a notable impact on accessibility of care for a significant patient group. If patients with no form of identification or no fixed address continue to be refused access to necessary primary care services, Romany and Traveller people will continue to face inadequate access to healthcare, and persisting health inequalities. For example, in a recent, and the largest ever, study on the health status of Liveaboard Boaters, we found that 37% of Boaters had previously been refused registration with a GP and that only 64% of Boaters reported having received an invitation to cervical or breast screening when they should have.<sup>24</sup>

## Digital-first registration

People within Romany and Traveller communities are more likely to experience digital exclusion as a result of educational inequalities and barriers to accessing data and devices as a result of factors such as deprivation, or limited access to Wi-Fi in rural locations. In 2018 we interviewed 50 people from Romany and Traveller communities across the UK to find out the extent of digital exclusion and identify barriers for Romany and Traveller people in digital participation.<sup>25</sup>

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<sup>22</sup> <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2019/04/patient-registration-standard-operating-principles-nov-2015.pdf>

<sup>23</sup> <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C1175-covid-19-primary-care-gp-practice-sop-v4.2-april-21.pdf>

<sup>24</sup> <https://www.gypsy-traveller.org/wp-content/uploads/2021/03/The-Health-Status-of-Liveaboard-Boaters-FINAL.pdf>

<sup>25</sup> <https://www.gypsy-traveller.org/wp-content/uploads/2018/09/Digital-Inclusion-in-Gypsy-and-Traveller-communities-FINAL-1.pdf>

We found that:

- One in five participants had never used the internet, compared to one in ten members of the general population.
- Over half of participants said that they did not feel confident using digital technology by themselves.
- Only two in five of those surveyed said that they use the internet daily, compared to four out of five of the general population.
- Only 38% of Romany and Traveller people (33% if housed) had a household internet connection, compared to 86% of the general population.

Whilst the COVID-19 pandemic has required services to adapt to new modes of service delivery, with the provision of remote consultation and online registration, the mystery shop exercise revealed a concerning trend of practices refusing to register people without digital access. The Guidance and Standard Operating Procedures for General Practice in the Context of COVID-19 states that *“Delivery of applications for patient registration may be by any means, including post and digital (e.g. scanned copy). Where a practice has online registration options, a supporting signed letter from the patient, posted or emailed to the practice, is acceptable to complete the registration”*.<sup>26</sup> Despite this, 11 practices out of 19 practices who would otherwise register our mystery shopper refused to register patients who were unable to use their online registration facilities. This will further serve to exacerbate barriers to primary healthcare for people experiencing digital exclusion in Romany and Traveller communities.

## **Support for patients with low or no literacy**

In addition to requesting to register with the practice, our mystery shopper queried whether assistance could be provided to complete any registration forms. Many people from Romany and Traveller communities have low literacy levels, and around 40% of our beneficiaries, report low or no literacy. The failure of services to offer accessible information and support with form filling can be a major barrier to accessing primary healthcare.

Two of the GP practices we contacted, out of 8 practices who would otherwise register our caller, stated that they would not be able to offer support with form filling

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<sup>26</sup> <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C1175-covid-19-primary-care-gp-practice-sop-v4.2-april-21.pdf>



to our mystery shopper. As of 2016, all services providing NHS care are required to follow the Accessible Information Standard (AIS).<sup>27</sup> This states that people in England have the right to accessible information and communication support, and services are legally obliged to meet these requirements. The AIS is primarily targeted at patients, service users, carers and parents, with a disability, impairment or sensory loss.<sup>28</sup> Despite this, many of the principles are relevant to communications with people with low literacy or low levels of English.

This finding indicates that more needs to be done to ensure that staff at GP practices are aware of the steps that can be taken to ensure an inclusive and accessible service, and to ensure that staff are fully aware and acting upon their duty to provide accessible communications. Simple adjustments, such as offering support to complete registration forms, can potentially improve accessibility for a significant number of patients across the population; around 16% of adults in England have low literacy skills.<sup>29</sup>

## Other

In total, four GPs cited other reasons for refusing to register our mystery shopper. These were:

- That the practice had reached a maximum number of patients overall, which is in line with NHS England guidance
- That the practice had reached a maximum number of temporary patients, which is not in line with NHS England guidance
- Requiring the details of our mystery shopper's previous GP, which is not in line with NHS England guidance
- Requiring a referral from the CCG before beginning registration, which is not in line with NHS England guidance

One practice who stated that they could not register patients with no fixed address, also stated that our mystery shopper would require a referral from the local authority before beginning registration, which is not in line with NHS England guidance.

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<sup>27</sup> <https://www.england.nhs.uk/wp-content/uploads/2017/08/accessible-info-specification-v1-1.pdf>

<sup>28</sup> NHS England (2016) 'Accessible Information Standard' <https://www.england.nhs.uk/ourwork/accessibleinfo/>

<sup>29</sup> National Literacy Trust (2017) 'Adult Literacy' <https://literacytrust.org.uk/parents-and-families/adult-literacy/>

## Conclusion

Romany and Traveller people face some of the most severe inequalities in healthcare access and outcomes among the UK population. The findings of our mystery shopping exercise suggest that, within the context of COVID-19, access to primary healthcare services for nomadic people has worsened, with very real risk that this will serve to further exacerbate the already stark inequalities Romany and Traveller communities face. There is an evident gap between policy and practice in terms of processes for registration for those with no fixed address or ID, and many practices fail to offer accessible registration processes to those with low or no literacy or experiencing digital exclusion. There is urgent need for systemic change across primary care services in England to ensure that nomadic people are able to access the care that they both need, and are legally entitled to.

## Recommendations

- The Secretary of State for Health and Social Care should make a clear commitment to ensure that patients who choose registration through non-digital means should be able to access all NHS healthcare settings.
- NHS England and NHS Improvement should develop a national and local accountability framework for GP registrations, in partnership with the Care Quality Commission and the voluntary sector.
- NHS England and NHS Improvement should introduce contractual obligations for GP practices to register patients who choose this through non-digital means, unless there are good clinical reasons to the contrary.
- NHS England and NHS Improvement should develop clear guidance and standards for providing accessible communications and appropriate supports to people with low or no literacy in healthcare settings.
- Clinical Commissioning Groups should commission voluntary sector organisations to mystery shop GP practices assessing issues around access within their area.
- Inclusion Health training should be mandatory for practice managers and GP receptionists.

## 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.

[www.gypsy-traveller.org](http://www.gypsy-traveller.org) | Telephone +44 (0)1273 234 777 | Email [fft@gypsy-traveller.org](mailto:fft@gypsy-traveller.org)

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