



**FRIENDS,  
FAMILIES &  
TRAVELLERS**

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# **Guidance Summary: Tackling Maternal Health Inequalities in Gypsy, Roma and Traveller Communities**

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## About us

Friends, Families and Travellers (FFT) is a leading national charity that seeks to end racism and discrimination against Gypsies, Travellers and Roma and to protect the right to pursue a nomadic way of life. We support individuals and families with the issues that matter most to them, at the same time as working to transform systems and institutions to address the root causes of inequalities faced by Gypsy, Roma and Traveller people.

Every year, we support over 1,300 families with issues ranging from health to homelessness, education to financial inclusion and discrimination to employment. Over half of our staff team, volunteers and trustee board are from Gypsy, Roma and Traveller communities.

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## Introduction

Gypsy, Roma and Traveller communities face stark inequalities in maternal health outcomes, associated with major barriers to accessing care services, among other factors. This guidance is designed to offer insights into the experiences of Gypsy, Roma and Traveller communities relating to maternity, and improve knowledge and understanding of how to approach the planning and provision of maternity services for these groups. Produced by Friends, Families and Travellers (FFT) in collaboration with Roma Support Group (RSG), this project was conducted as part of the Health and Wellbeing Alliance, which is supported by the Department of Health and Social Care.

The guidance draws on a review of existing literature, primary data collection via surveys and focus groups, as well as anecdotal insights from the work of Friends Families and Travellers and Roma Support Group. The insights and voices of members of the Gypsy, Roma and Traveller communities were prioritised in every stage of the research process, in order to ensure that the guidance authentically reflects the experiences and needs of these groups.

The aim of this guidance is to:

- Improve knowledge and understanding within the health and care system of the maternity inequalities and maternal healthcare needs of Gypsy, Roma and Traveller communities.
- Improve knowledge and understanding of how to approach maternity planning in Gypsy, Roma and Traveller communities.
- Amplify the voices of Gypsy, Roma and Traveller community members, and provide guidance on ensuring that members of the community are included in the planning and provision of maternity services.

This resource is designed to support all professionals who provide maternal health and care services to people in the Gypsy, Roma and Traveller communities.

It is important to note that while this guidance is aimed at addressing inequalities in maternity services for Gypsies, Roma, and Travellers, not all members of these communities will have the same problems in accessing care and some may not necessarily experience the barriers outlined.

The extended guidance, which includes a full methodology, literature review and background information on Gypsy, Roma and Traveller communities, can be [viewed here](#).

## Summary of key research findings

The key findings we have drawn from our research can be summarised as follows:

- **Lack of effective communication and accessible information** in health services.
- **Barriers to accessing and maintaining continuity of care** for Gypsy, Roma and Traveller communities.
- **Wider determinants of health**, such as chronic shortages of Gypsy and Traveller sites, and insecure housing experienced by some members of the Roma community.
- **Discrimination, both direct and structural**, within public services in healthcare and beyond.
- **Fear and mistrust** of public services and state bodies.
- **Lack of awareness, sensitivity and accommodation** of cultural norms, such as those relating to maternity care.
- **Stigma and taboo around perinatal mental health**, as well as barriers to accessing mental health support.
- **High rates of Caesarean birth reported by Gypsy, Roma and Traveller research participants** and consulted health professionals.
- **High rates of Classical Galactosemia** among infants born to Irish Traveller parents.
- **High rates of miscarriage, pregnancy loss and/or child loss** reported by Gypsy, Roma and Traveller research participants.

## Summary of key recommendations:

Based on these findings, our main recommendations are as follows:

- **Gypsy, Roma and Traveller inclusive services training should be mandatory** within all health and social care services.
- **Health and social care services should be adapted to accommodate specific cultural norms** and requirements, as well as nomadic ways of living.
- **Carefully review Caesarean birth indications** and ensure the patient is fully informed about their condition and care.
- **Carefully review breastfeeding support and education practices in line with cultural norms** found within Gypsy, Roma and Traveller communities.
- **Service providers should be aware of higher rates of Classical Galactosemia** among children born to Irish Traveller parents.
- **Baby loss and bereavement support services and materials must be made accessible** and culturally appropriate for Gypsy, Roma and Traveller parents.
- **NHS England should develop clear guidance on accessible communication**, and prioritise this for patients and service users.
- **Service providers should engage directly with Gypsy, Roma and Traveller populations** and voluntary organisations on a local and national level.

## Research findings: tackling inequalities in maternity care for Gypsy, Roma and Traveller communities

### Theme 1: Communication and accessible information

A key theme emerging from the data and insights is the issue of effective communication and accessible information.

Several Gypsy, Roma and Traveller participants noted experiences of poor or inconsistent communication from care providers, resulting in confusion and stress. One participant discussed the poor communication relating to a traumatic birth experience. The participant was unable to access medical notes after their emergency Caesarean section reverted to vaginal birth. They noted that the event was not explained clearly, and they were given contradicting accounts of what happened:

***“They wouldn’t tell me what they were doing for a very, very long time... Because of what I went through, if I were to have another [pregnancy] I’d be under special care... I’ve got PTSD.”***

#### 1.A Literacy levels

Within many Gypsy, Roma and Traveller communities, there are high levels of low to no literacy. FFT service user data reveals that 47% of FFT clients have low or no literacy, findings which are corroborated by several broader external studies on Gypsy, Roma and Traveller communities generally<sup>1</sup>. Large percentages of Roma communities across Europe are reported to be effectively or functionally illiterate<sup>2</sup>, data which corresponds to the anecdotal evidence of Roma Support Group staff experiences.

This can be a major barrier to accessing essential services and information, due to difficulties with form-filling or understanding important information when provided in written formats, such as letters or leaflets. This can mean that patients miss appointments or do not understand advice and care instructions. Embarrassment associated with needing to disclose issues around literacy can also prevent individuals from asking for support with this.

One focus group participant pointed to a lack of understanding about literacy issues among care providers:

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<sup>1</sup> [Liegeois and Gheorghe \(1995\); Fraser \(1995\); Levinson \(2007\); Greenfield et al. \(2007\)](#)

<sup>2</sup> [European Union Agency for Fundamental Rights \(2014\). Roma survey – Data in focus Education: the situation of Roma in 11 EU Member States](#)

***“You went to school, you can read it” was a midwife’s response to asking for help with a leaflet. At which point the participant walked out of the surgery and only returned when their usual midwife was back, and felt that the previous midwife’s mistreatment had been dealt with.***

Some participants noted positive experiences in this area, particularly when information was made accessible by staff who carefully and respectfully provided support by reading and explaining written documents:

***One participant noted that despite being unable to read, they felt that they did not miss out on any information because “I’d get them to read it out and explain it to me”.***

### **1.B Language barriers**

Roma groups in particular may have low levels of fluency in English<sup>3</sup>. Many migrant Roma people have reported struggling to understand written material in English, or medical terms in both English and their first language (usually one of the Romanes dialects) or second language (often a Central or Eastern European language).<sup>4</sup>

Patients who cannot communicate effectively in English are entitled to an interpreter or health advocate, however, further barriers arise for Roma communities due to a lack of professionals who can speak and/or interpret Romanes. It is important to note that due to cultural taboos around discussing health issues, calling on family members to act as interpreters is not appropriate and can result in patients not disclosing important information about their symptoms.

One Roma research participant explained that:

***“The number one thing that’s missing from maternity care is language support. I was told to bring my daughter to translate for me.”***

### **1.C Digital exclusion**

Gypsy, Roma and Traveller communities experience high levels of digital exclusion. Previous FFT research found that over half of Gypsy, Roma and Traveller individuals surveyed did not feel confident using the internet, with low literacy levels, cost, poor signal and data poverty indicated as the key barriers to internet usage<sup>5</sup>.

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<sup>3</sup> Roma Support Group (2022) [Language barriers and communication](#)

<sup>4</sup> Roma Support Group (2022) [Language barriers and communication](#)

<sup>5</sup> Friends Families and Travellers (2018) [New report reveals significant digital exclusion in Gypsy and Traveller communities in the UK](#)



One participant explained:

***“I go to McDonalds to do all the updates on my phone – but you have to make sure you have a full battery on your phone, or it won’t work. McDonalds Wi-Fi is free and it’s a good tip to use this, so you can do stuff without eating up your data. It’s hard though, because lots of my friends can’t read or write, so it’s no use.”***

Only 38% of Gypsy and Traveller people (33% if living in bricks and mortar) had a household internet connection, compared to 86% of the general population.<sup>6</sup>

Roma people also experience high levels of digital poverty, lacking adequate technology and equipment such as smartphones and laptops<sup>7</sup>. A lack of digital skills to engage with the internet and other digitised platforms also prevents Roma people from engaging in a meaningful way<sup>8</sup>.

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, this has significantly exacerbated barriers to healthcare services.

### **Recommendations:**

- **Ensure resources are tailored** to the patient’s level of literacy.
- **Ensure staff and care providers can work with patients with low or no literacy.**
- **Best practice for interpreting would include working with bilingual Roma advocates**, who are ideally able to communicate in the patient’s first language.
- **Produce information for distribution by GPs** in community languages.
- **Ensure resources are** culturally sensitive.
- **The Secretary of State for Health and Social Care should commit** to ensuring all NHS healthcare settings can be accessed through non-digital means.
- **NHS England should develop clear guidance on accessible communication** for patients with low to no literacy.

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<sup>6</sup> Friends Families and Travellers (2018) [New report reveals significant digital exclusion in Gypsy and Traveller communities in the UK](#)

<sup>7</sup> Lawforlife (2021) [Digital exclusion and Roma communities in the context of child protection](#)

<sup>8</sup> Lawforlife (2021) [Digital exclusion and Roma communities in the context of child protection](#)

## Theme 2: Nomadic living and accessing care

### 2.A Nomadic living

Participants noted that some services and service providers did not seem to have a clear understanding of nomadism, and nomadic ways of life. Therefore, often nomadic members of Gypsy, Roma and Traveller communities did not feel that services understood their needs, or that services were designed with them in mind.

***One participant stated, “I think that things won’t change for Travellers; they [services] need to understand us and change with the times”.***

Participants noted that people living on roadside camps are often considered statutorily homeless and will therefore be seen by specialist midwives. Depending on the nature of the midwife’s specialism this may not be appropriate, as the needs of nomadic people are not necessarily the same as those of people experiencing homelessness.

A piece of good practice reported by nomadic participants, is the provision of handheld medical notes. Participants stated they had been given handheld notes while they were travelling during their pregnancies, to help with communication across services. However, participants noted that this was rare, and that most of the time services weren’t communicating about their care.

### 2.B Accessing services and continuity of carer

Moving around during pregnancy can lead to issues with accessing care, maintaining continuity of carers, and problems with communication across different services.

#### ***Registration***

Members of Gypsy, Roma and Traveller communities in the UK face many barriers to accessing primary care services. A major barrier is the wrongful refusal of registration, based on not being able to provide a fixed address. Provision of a fixed address or proof of identity is not a requirement for registration at GP services. However, a ‘mystery shopping’ exercise conducted by FFT found that 74 out of 100 GP surgeries in England broke NHS England guidance and refused to register a new patient because they were unable to provide proof of identity, proof of fixed address, register online or another reason.<sup>9</sup>

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<sup>9</sup> Friends, Families & Travellers (2019) [No room at the inn: How easy is it for nomadic Gypsies and Travellers to access primary care?](#)

Gypsy, Roma and Traveller communities therefore struggle to access basic services they are entitled to. Some Gypsy, Roma or Traveller patients may only come to register with a GP upon becoming pregnant, and report experiencing serious delays in routine prenatal checks and scans due to difficulties registering.

### ***Waiting lists***

Moving around or living nomadically can pose issues relating to waiting lists. FFT often hears from people living nomadically who have experienced disadvantage on NHS waiting lists which affects their access to, experience of and outcomes from NHS services. Patients are often forced to start from scratch when moving to a new area or are removed from waiting lists when travelling, which means health needs are often not addressed until they have reached an acute stage.

In terms of maternity care, this can mean that people who have experienced traumatic or complicated births may never reach the top of waiting lists for secondary mental and other perinatal healthcare services, when moving across geographical boundaries.

### ***Continuity of carer***

A consistent message from focus groups and surveys was that continuity of carers and maintaining a relationship with the same midwife throughout pregnancy, was important.

One participant spoke of a positive experience, having built a good relationship with a midwife who visited them at home on a Traveller site:

***“...it was good because she came on the site.”***

Other participants mentioned that not all midwives were happy to do postpartum visits on sites.

## **2.C Accommodation and wider determinants of health**

Living conditions have a powerful influence on overall health and wellbeing; while issues across the wider determinants remain unaddressed, the effectiveness and benefits of medical intervention are diminished<sup>10</sup>. Gypsy, Roma and Traveller communities can experience chronic exclusion across the wider social determinants, with many people facing multiple inequalities including deprivation, difficulty accessing adequate accommodation, inequalities in education, and barriers to employment. 10,000 Gypsies and Travellers have no place to stop as a result of a

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<sup>10</sup> The Marmot Review (2010) [Fair Society, Healthy Lives](#)

chronic national shortage of sites, and 3,000 families without a permitted stopping place have limited or no access to basic water and sanitation.<sup>11</sup> Evictions from roadside camps during pregnancy can disrupt care and compromise patients' positions on waiting lists. Wider issues around national policy relating to the provision and quality of Traveller sites are a key factor in maternal and general health inequalities experienced by these groups.

Accommodation issues can be a major factor contributing to delays in accessing maternity services for Roma parents. Living in unstable, shared or overcrowded accommodation without formal rental agreements can lead to reluctance to access available support, due to fears around eviction or social services intervention. An inability to provide documentation as proof of address can also lead to difficulties registering for GP or maternity services.

### **Recommendations:**

- **Prioritising accessibility and flexibility in care provided to Gypsy, Roma and Traveller communities is crucial**, in order to combat the barriers associated with nomadic living.
- **Ensure patients facing digital exclusion** are able to book appointments,
- **Collecting data on the wider determinants of health** can help tailor services.
- **Consider how your service can support** the wider determinants of a patient's health.
- **NHS England should create a clear information resource for clinicians** on responsibilities to nomadic people.
- **NHS England should partner with voluntary sector organisations and nomadic communities** to develop information for nomadic patients.
- **The Department for Levelling Up, Housing and Communities should develop and implement a national cross-government strategy to tackle the inequalities** experienced by Gypsy, Roma and Traveller communities.

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<sup>11</sup> MHCLG (2019) Traveller caravan count: January 2019

- **Policymakers across Government should routinely adopt a “Health in All Policies” approach to decision-making**, with consideration of poor health outcomes faced by Gypsy, Roma and Traveller communities.
- **NHS England should develop a national and local accountability framework for GP registrations**, in partnership with the Care Quality Commission and the voluntary sector.
- **Integrated Care Boards should commission voluntary sector organisations to mystery shop GP practices**, to assess accessibility.
- **Inclusion Health training should be mandatory** for practice managers and GP receptionists.
- **NHS England should update the Patient Registration Standard Operating Principles** to clarify the grounds for refusal of nomadic patients who travel outside of practice boundaries, and for nomadic patients’ right to register as permanent patients in one practice.

### **Theme 3: Discrimination**

Experiences of (and fear of) discrimination can be a major barrier to Gypsy, Roma and Traveller patient engagement with health services, in maternity care and beyond. The Equality and Human Rights Commission found that 44% of the British public report having a negative opinion about Gypsies, Roma and Travellers, demonstrating the high levels of social exclusion and discrimination faced by people from these communities.<sup>12</sup>

#### **3.A Direct discrimination**

Survey and Focus Group participants unanimously felt that they were treated differently within healthcare services because of their Gypsy, Roma and Traveller background. One participant stated that when their surname is mentioned,

***“That’s when they give me dirty looks.”***

One Roma research participant expressed that,

***“I think health professionals have an allergy to Roma people.”***

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<sup>12</sup> Equality and Human Rights Commission (2018) [Developing a national barometer of prejudice and discrimination in Britain](#)

Another participant stated that they found their midwife to be condescending and rude, stating that,

***“I think they knew my ethnicity, and they didn’t interact with me as much after that.”***

Several participants mentioned having previously had access to a (no longer functioning) Midwife Hub, which offered a midwife who was part of a Gypsy or Traveller community. This led to significantly higher engagement, as they felt that their home situation was better understood:

***“She’s very good because she goes on site and she knows you know what, it’s, you know. She knows about Travellers. It’s not like she’s gonna ask silly questions like, ‘Where do you get your water from? Where will you sleep?’ and stuff like that.”***

However, other participants said that they had been automatically assigned the midwife who was part of a Gypsy or Traveller community, and would have preferred to have the midwife linked to their GP.

Roma research participants discussed various experiences of stereotypical attitudes or assumptions on the part of health and maternity specialists, including persistent and unfounded questioning around domestic violence. Another recurring issue related to professionals persistently questioning Roma patients around a perceived lack of participation or engagement on the part of their male partners. In many Roma communities, it is often not considered culturally appropriate for men to attend medical appointments or be present in the delivery room. Several Roma research participants explained that their care providers did not understand this, repeatedly questioning them around this issue and even mentioning social services, which caused a great deal of anxiety for the patients and their families.

### **3.B Structural and systemic discrimination**

In addition to discriminatory practices relating to wrongful refusal for registration at services, participants reported several issues relating to structural or systemic discrimination by public services while living on Gypsy and Traveller sites.

Participants who were living on a site during their pregnancies stated that they felt that services often held discriminatory views about sites and would not conduct outreach.

Several participants reported being inappropriately assigned a Drug & Alcohol Specialist midwife, or that only Drug & Alcohol Specialist midwives were willing to

make site visits. Some participants explained that they had experienced subsequent repercussions within services as a result of this.

One participant stated that this had direct consequences for how they were treated during subsequent pregnancies. Without their knowledge, this had meant their records flagged them as being an intravenous drug user, and they had been asked to undertake urine sample drug testing throughout their pregnancy. They were also told that they would not be allowed to take their children to the bathroom with them, because professionals believed they were swapping their urine samples. They stated that this was all as a result of midwives not wanting to visit sites due to prejudicial views, and they were fearful that this would have significant knock-on consequences with social services.

Participants stated that they were aware of other instances of this issue. One participant stated that they knew someone whose baby had been given methadone after their birth, because it was incorrectly recorded on their notes that they were an intravenous drug user, despite no history of drug use. Although unverified, perceptions such as these reflect the presence of a deeply ingrained fear of unfair treatment by health services. One participant stated:

***“It’s depressing. It’s just so archaic, all of this”.***

Reports of systemic discrimination were not limited to health services. One participant described their experience of a home birth on site. They reported that someone walking past had heard screams and immediately alerted the police. They stated that due to prejudice within police services, the response was extreme and disproportionate, with armed police arriving at their home while they were in labour. They stated:

***“You’re supposed to have a right to a home birth in this country.”***

### **Recommendations:**

- **Gypsy, Roma and Traveller inclusive services training should be mandatory** within all health and social care services.
- **DHSC, NHSE&I and local Integrated Care Systems should routinely commission and build capacity** for Gypsy, Roma and Traveller VCSE organisations and assertive outreach services to provide a key bridge between healthcare services and communities.



- **Drug & Alcohol Specialist midwives should be renamed** as “Inclusion Health Midwives”, to remove potential stigma and taboo of visits.
- **Local services should prioritise engagement with communities** to build trusting relationships (see more under Theme 4).

## **Theme 4: Fear and mistrust**

Fear and mistrust of state bodies and state services has been a recurring theme found in FFT and RSG research. Concerns around discrimination mean that many Gypsy, Roma and Traveller people may be reluctant to engage with health and care services. Previous poor experiences on accessing services can further damage trust. As such, many Gypsy, Roma and Traveller people may put off attending health services when issues arise, meaning that needs may not be identified until they have reached an acute stage.

Many participants were reluctant, or felt uncomfortable, about disclosing ethnicity, for fear of discrimination or that their culture wouldn't be well understood within services. Many participants were particularly fearful of social services involvement.

Trust is a major aspect of any relationship between Gypsy, Roma and Traveller communities and health professionals, as knowledge of pockets of good practice is spread among the communities quickly. If one service has a good reputation among community members, then this will be cascaded to family and friends for them to attend the service also. More than 34% of professional survey responses mentioned trust as a key enabler to good practice at least once.

### **4.A Fear of social services involvement**

Some participants reported fears around social services involvement, which made them hesitant to interact with health services or seek support when needed.

One participant stated that she feared social services involvement, and this had put her off accessing maternity services. She stated:

***“I don't feel like they'll understand my culture. I feel like I have to agree to their terms, or they'll take the kids away. A lot of Traveller women hide things because of that.”***

This sentiment was mirrored by another participant, who stated that maternity services made them feel “**pressured**”, and said:



***“You feel afraid that your culture won’t be understood, and scared of social services and what they’ll do because they don’t understand. I’ve never met a decent social worker”.***

Another participant stated that they had struggled with their mental health after giving birth, but noted:

***“I have only recently spoken to my GP about depression because I was afraid they’d call social services. I don’t want to mention mental health.”***

Another participant noted that they felt they had to be compliant with services to avoid causing any trouble, or any risk of social services being involved. They stated:

***“Whatever they told me, that’s what’s going to happen. I just did what they told me to do”.***

One participant shared that they had been referred to social services for help for accommodation, but when they arrived at the appointment without the initial referring midwife being present, it became a safeguarding referral about their ability to look after their unborn child. They were then put on an at-risk register with multiple interventions, despite their explanations. They felt that the eventual apology from the care services did not make up for the anxiety and trauma caused by this chain of events.

### **Recommendations:**

- **Gypsy, Roma and Traveller inclusive services training should be mandatory** within all health and social care services.
- **DHSC, NHSE&I and local Integrated Care Systems should routinely commission and build capacity** for Gypsy, Roma and Traveller VCSE organisations and assertive outreach services to provide a key bridge between healthcare services and communities.
- **Build trust with community members** through direct engagement.
- **Carefully review all referrals** to social services.
- **Understand that reticence around home visits may be anchored in concerns about negative perceptions** of nomadic living or insecure housing.

- **Ensure that any promises or commitments made to patients are followed through**, to help build relationships and avoid broken trust.

## **Theme 5: Cultural norms around gender, maternity and health**

### **5.A Gender and cultural norms/requirements**

A frequent topic mentioned in survey and focus group responses was a lack of awareness of, or accommodations made for, cultural norms and requirements around gender.

Within many traditional Gypsy, Roma or Traveller families, there are important cultural preferences regarding gender in healthcare. For many individuals, it can be difficult to openly discuss health concerns with a professional of another gender. This can also be the case when in the company of any person of another gender, or an older person, including family and friends. This applies to general health-related topics, but especially to gender-specific care, sexual health and mental health.

Lack of same-gendered staff can therefore be a barrier for Gypsy, Roma and Traveller patients to access services.

One survey respondent wrote:

***“Didn’t go back after first access to one place as couldn’t see a woman & couldn’t talk to a man.”***

Participants noted that many Gypsy, Roma and Traveller women can feel uncomfortable being treated by male professionals or having male partners in the room during labour. They stated that these gender dynamics are part of their cultures, but that this wasn’t well understood by services.

One participant noted that a man had walked into their hospital room during the night when they had given birth. They stated:

***“A male doctor came into the room and touched me. I was really uncomfortable. I was only 16 years old, and I felt really violated.”***

Participants agreed that experiences like these could make them more reluctant to access care in the future.

Another participant stated that they had felt very uncomfortable having an examination by a male staff member, but felt that the significance of this wasn't taken on board by services, and that when they had expressed this they were told:

***“You'll be seen by whoever's on shift.”***

Lack of same-gendered staff, and lack of awareness or adjustments around cultural norms relating to gender, was discussed as an important barrier to accessing care for Gypsy, Roma and Traveller people.

It is also important to be aware that patients may not feel comfortable speaking openly with other people present. For care providers, offering a warning that you will need to ask about potentially sensitive topics can be helpful in facilitating a more open conversation.

Some Roma research participants explained that they had been asked to provide their own interpreters for appointments. Due to small social networks and/or limited financial resources, they had to rely on family members. Discussion of health issues in front of family members, particularly those of different genders or generations, is often felt to be culturally inappropriate for Roma communities. Reliance on family or friends for translation services can therefore lead to failures in communication and leave patients unwilling to openly discuss their health concerns.

## **5.B Cultural norms around maternity**

### ***Ante and postnatal care***

Among certain Gypsy, Roma and Traveller communities, antenatal and postnatal care may not be a cultural norm or expected as standard practice for a healthy pregnancy. It is therefore important to explain what services and types of care are considered routine within the NHS maternity pathway, and why.

In some migrant Roma communities, a lack of ante and postnatal care in their home countries is linked to a lack of understanding about the importance of antenatal care. This may lead to mistrust of home visits unless it is explained that they are routine.

Discussing priorities and positive experiences in postnatal care, several Roma participants highlighted that the ability to hold their baby straightaway and having a birthing partner present were both seen as very important positive practices.

### ***‘Purity Period’***

Some traditional Gypsy, Roma and Traveller communities observe a custom sometimes known as a ‘purity period’ after birth. It is important to be aware of traditions associated with this custom, in order to factor them in to postpartum service planning for patients who observe.

After birth, observing mothers will not be expected to leave the home, and will be supported by female family or community members with tasks like cooking and cleaning, to allow time for mother and child to bond. Male community members might not be present during this time, potentially including the child’s father. The time periods involved can vary, typically ranging from a few weeks to around three months after birth.<sup>13</sup>

This custom is sometimes known as a ‘purity period’, but many people may know of it under a range of different names.

## **5.C Breastfeeding**

Some participants raised the issue that many women in the Gypsy, Roma or Traveller communities may not feel comfortable breastfeeding in certain contexts for cultural reasons, but that this is not always well-understood or accommodated for within services.

A number of participants agreed that they felt they had been pushed by midwives to breastfeed in a way that had made them feel uncomfortable.

One participant stated that a Specialist Midwife had pushed them to breastfeed with their male partner in the room, which they had felt very uncomfortable with. They then said they felt judged as being **“too traditional”**, and stated:

***“I didn’t want my partner in the room, but they look at you differently after that.”***

Another participant described an experience where a midwife had...

***“pulled down my gown and put the baby there”,***

...without first asking for consent to do so. They noted that they had felt humiliated and violated by this, but that the midwife didn’t appear to have any awareness of why this was so uncomfortable for them.

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<sup>13</sup> Roma Support Group (2022) [Maternity Services](#)

One participant stated that they had not been given the option to combination feed, despite feeling this would be the best option for them. They noted that they wanted to breastfeed at night, when they knew they would have the privacy to do so, and then bottle feed during the day.

One participant noted that many women feel more comfortable using a pump, as skin to skin contact during breastfeeding was seen to be inappropriate or uncomfortable. She said:

***“Whatever you choose, they should recommend whatever makes someone feel more comfortable.”***

Breastfeeding may not be considered the norm in all Gypsy, Roma and Traveller communities, so among certain groups awareness around the benefits and practicalities of breastfeeding may be low. However, when provided with thorough, accessible, non-judgemental, and culturally relevant guidance on the benefits of breastfeeding, as well as practical support in doing so, many parents were keen to adopt it.

One participant noted that they had experienced completely different care with the births of their first and second children. They stated that the younger child’s birth was more person centred, that they were provided with options and choices throughout, and that the midwife was calming and checked how they felt. They stated that they weren’t pressured to breastfeed but were given lots of information about it in a clear way, which they found helpful.

Another participant stated that even if it was unusual in their community, they continued to breastfeed as they knew it was good for the child.

Another participant stated that while they were in hospital someone came to visit to give information about breastfeeding. They said:

***“When I was in hospital a different nurse came to see me to talk all about breastfeeding. I didn’t feel comfortable with breastfeeding, but she gave me leaflets and talked to me for an hour. She told me breast milk could help with the baby’s immunity and I was gobsmacked. I asked her loads of questions and she explained it clearly. She showed me how to tuck the baby round so he’s comfortable. She made me feel like it wasn’t just a nurse pressing down on me, telling me what I should or shouldn’t do”.***

For many in the Roma community, breastfeeding is more generally encouraged and seen as important for a baby’s health. However, due to cultural sensitivities, older

Roma women are not likely to provide support and advice to young mums around the practicalities of breastfeeding. This often leads to difficulties for new mums in learning how to latch, or perceived problems in milk supply. Some Roma parents report initially intending to breastfeed, but resorting to other feeding methods due to lack of breastfeeding support. [This blog](#) provides further perspectives on this, from the Roma community.

## 5.D Perinatal mental health

There is significant stigma and taboo around mental health within many Gypsy, Roma and Traveller communities. Awareness and openness around mental health issues is gradually improving, but there remains a significant reluctance to discuss mental health.

Some participants referred to fears within their communities that disclosing mental health issues such as postpartum depression to professionals may cause social services to intervene and take children away. This was linked to historic instances of people being deemed “*mental*” and being institutionalised.

Specifically for some Roma groups, there is a belief that mental health problems are genetic and run in the family, meaning it is rarely discussed for fear of damaging the family’s reputation or children’s future chances of finding a marriage partner. The community’s common language, Romanes, also lacks the vocabulary to describe mental health problems such as depression and anxiety attacks, as well as a range of different emotions, which can create barriers to accurate self-expression and diagnosis.

When mental health is discussed, it may not be referenced as such. Many from Gypsy and Traveller communities will refer instead to having trouble with ‘nerves’ or having ‘bad nerves’. There is some awareness of postpartum depression within these communities, but it may be referred to as bad nerves, ‘the baby blues’ or ‘after-birth stress’.

### Recommendations:

- **Conduct training for staff around cultural norms and requirements** for Gypsy, Roma and Traveller patients around gender and make suitable accommodations within services, such as offer same-gender care providers.
- **Engage with community knowledge and traditions** which can complement and enhance that of health care professionals.

- **Ensure Roma women observing the post-partum ‘purity period’ are not excluded from postnatal care** and be aware of cultural norms such as the father not being present during this time.
- **Explain in advance and then again at the time what home visits will be about and what will happen**, including potentially physically examining bodily areas traditionally regarded as taboo.
- **Consider who else is in the room when conversations are held** and ensure that the patient feels comfortable speaking openly.
- **Ensure you provide official interpreters** and do not use children or other family members as interpreters, especially when relating to gynaecological matters.
- **Be aware that pre and postnatal care might not be viewed as a standard part of a health pregnancy**, and ensure patients understand what care is routine and preventative.
- **Be aware that breastfeeding may be an uncomfortable and taboo topic** for some patients from Gypsy, Roma or Traveller communities.
- **Cater for postpartum depression in a culturally sensitive manner, emphasise availability of mental health services**, and be aware of reluctance to disclose mental health issues. .
- **Produce and distribute accessible and culturally relevant resources and education** on perinatal mental health.

## **Theme 6: Experiences of Caesarean birth**

A major issue revealed in focus group discussion and survey responses was unusually high rates of Caesarean birth among participants. Reports of patients undergoing 4+ Caesarean births are not uncommon in accounts from community members, a trend which was also flagged by the Health Inclusion Officer at a major hospital. Moreover, Gypsy, Roma and Traveller participants report undergoing Caesarean birth for reasons they were unclear about or had not been adequately explained to them. FFT’s anecdotal evidence suggests that inequalities, biases and barriers to accessing maternity care and education could lead to higher Caesarean birth rates even when not medically indicated. One participant explained that their Caesarean birth was:



***“the most traumatic experience of my life - no one ever explained to me why I was taken into theatre.”***

Among Roma women, preferences often tend toward avoiding Caesarean births, unless otherwise advised. For some, this is associated with [histories of forced Caesarean birth and forced sterilisation](#).

## **Recommendations**

- **Carefully review the need for a Caesarean birth and ensure the patient is fully informed** about their condition and care.

## **Theme 7: Experiences of baby loss and miscarriage**

The final major theme emerging from this research process, is experiences of pregnancy or infant loss. As outlined in the Literature Review, Gypsy, Roma and Traveller communities experience high rates of miscarriage and child loss—a dynamic which was evident in focus group discussion and survey responses.

When prompted, every FFT focus group participant reported experiencing the loss of a pregnancy or of a child. However, none of the participants stated that they had received any kind of professional support following these experiences.

One community member recounted:

***“When I had my first miscarriage, I was living roadside with very little understanding of what was happening to me. I couldn't get a midwife to come to the site and had no access to toilets or shower. The longer-term effects on my mental health became clear when I had my second child and suffered with postnatal depression, partly due to unresolved grief. I have now had a number of miscarriages and ectopic pregnancy and it doesn't get easier - nobody from healthcare has ever asked me or offered any support around grief.”***

In many Gypsy, Roma and Traveller communities, issues relating to both pregnancy and mental health might not be openly discussed. Stigma and taboo around these topics can mean that individuals and families navigating issues like trauma relating to miscarriage or baby loss might be very reluctant to seek support.

## **Recommendations**



- **Be aware that miscarriage, pregnancy loss or infant loss can be an extremely sensitive subject**, particularly among Gypsy, Roma and Traveller patients.
- **Experiences of losing a child or pregnancy might not be discussed openly** within the respective community.
- **Due to broader taboos and stigma around discussing mental health and/or pregnancy**, patients may not have talked about their experiences or received support around previous birth trauma or trauma from baby loss.
- **Develop accessible and culturally relevant bereavement support materials and services** for Gypsy, Roma and Traveller parents.

## General Recommendations

Earlier recommendations were grouped according to particular themes. The following recommendations, however, are broader principles that can be relevant for any of the issues mentioned above, and more.

1. **Provide Gypsy, Roma and Traveller inclusive training for all staff, and implement the lessons learned to normalise cultural adjustments in service provision.**
2. **Work collaboratively with voluntary and community organisations to bridge the gap between patients and the health service.**
  - a. View FFT's [Services Directory](#) for further information.
  - b. Voluntary sector organisations providing specialist bereavement and traumatic birth support should work closely with Gypsy, Roma and Traveller communities, ensuring they are accessible and engaging appropriately.
3. **Ensure your services are accessible by prioritising flexibility and accessibility for those with digital, literacy or communication barriers.**
  - a. NHS England should develop clear guidance and standards for providing accessible communications and appropriate supports to people with low or no literacy in healthcare settings.
4. **Ensure your communication methods are effective.**

- a. Verbal communication should be given preference when explaining information and notes to Gypsy, Roma and Traveller patients, rather than relying on written leaflets or notes. Encourage in-person meetings or telephone calls where possible, to combat digital exclusion.

**5. Consider the wider determinants of health and how your services can support your community more broadly.**

- a. For example, public health leads can work to ensure local authorities are supporting negotiated stopping for people living on roadside camps.

**6. Prioritise hiring staff from within the marginalised communities you serve.**

- a. Increasing the representation of Gypsy, Roma and/or Traveller staff in health services can help build trust and ensure community needs are understood, and voices heard.

**7. Tackle Gypsy, Roma and Traveller invisibility in datasets by getting to know your local communities and their needs through an engagement and research-based approach—tailor your services accordingly.**

- a. Gypsy, Roma and Traveller people should be included at every level of discussion, co-production and distribution of resources, services, and advocacy.
- b. Collect your own data or carry out analysis of other available data locally to build your understanding of local population sizes.

## About us

Friends, Families and Travellers is a leading national charity that seeks to end racism and discrimination against Gypsies, Travellers and Roma, regardless of ethnicity, nationality, culture or background, whether settled or mobile, and to protect the right to pursue a nomadic way of life.

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