



**FRIENDS,
FAMILIES &
TRAVELLERS**

May 2023

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

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Acknowledgements

Our thanks go to the following for their invaluable input, feedback, and case studies for this resource; Emma Bray of Friends, Families and Travellers, Mihai Bica of [Roma Support Group](#), [Race Equality Foundation](#), [British Red Cross](#), [Faith Action](#), [Tommy's and Sands Maternity Consortium](#), [Queen's Nursing Institute Gypsy, Roma, Traveller, Roma and Boater Network](#) and Lisa Ramsey of NHS England for their guidance throughout this project, as well as all the Gypsy, Roma and Traveller people that attended focus groups and shared their experiences for this report.

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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Executive Summary

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. The guidance draws on 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 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.

Key Issues:

- **Lack of effective communication and accessible information in health services.** These relate primarily to high rates of low literacy, language barriers, and digital exclusion experienced by Gypsy, Roma and Traveller communities.
- **Barriers to accessing and maintaining continuity of care for Gypsy, Roma and Traveller communities.** These barriers can relate to a lack of knowledge or inclusion within services for the nomadic way of life of some Gypsy and Traveller communities. For some Roma patients, challenges can arise due to frequent changes in residence, often linked to poor housing or changes in employment.
- **Wider determinants of health.** These often relate to chronic shortages of Gypsy and Traveller sites and the poor quality of facilities on those that are provided, as well as issues with poor 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**, on the part of many in the Gypsy, Roma and Traveller communities.
- **Lack of awareness and accommodation in services around cultural norms**, relating to the gender of service providers and cultural taboos around certain health topics.
- **Lack of awareness and sensitivity around cultural norms relating to maternity care and practices**. This is particularly relevant to approaches to breastfeeding and postpartum customs.
- **Stigma and taboo relating to perinatal mental health**, as well as barriers to access for mental health support.
- **High rates of Caesarean birth reported by Gypsy, Roma and Traveller research participants**, as well as 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**, with very few participants having received any professional support relating to these experiences.

Key Recommendations:

- **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.
- **Prioritise clear, effective, and accessible communication for patients and service users facing barriers relating to literacy, language and digital exclusion.** Verbal communication methods should be preferred when explaining information and handheld notes to Gypsy, Roma, and Traveller mothers, instead of issuing leaflets.
- **NHS England should develop clear guidance and standards for providing accessible communication** and appropriate support to people with low or no literacy in healthcare settings.
- **Service providers should engage directly with Gypsy, Roma and Traveller populations and voluntary organisations on a local and national level, to ensure community voices are heard and their needs met.** This may require developing new engagement approaches, rather than relying on existing routes.

Introduction

This guidance has been produced by Friends, Families and Travellers (FFT) in collaboration with Roma Support Group (RSG), through work conducted as part of the Health and Wellbeing Alliance, which is supported by the Department of Health and Social Care.

The resource will outline its aims and research methodology, before providing a literature review of existing data on maternal health inequalities within the Gypsy, Roma and Traveller communities. Research findings will then be outlined, structured by the main themes drawn from primary data collection. Each section will offer relevant recommendations to maternity health and care service providers and policy makers, before concluding with more general recommendations.

Aims

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 these communities 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. This includes, but is not limited to:

- Frontline health and care professionals working within maternity care;
- Commissioners;
- Policy leads;
- Voluntary sector organisations.

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.

Methodology

In developing this resource, FFT conducted a scoping exercise to assess existing evidence and research gaps relating to Gypsy, Roma and Traveller experiences of maternal health inequalities and healthcare services. The learnings from this process are summarised in the Literature Review section of this guidance.

FFT then established a working group of Gypsy, Roma and Traveller community members who could contribute insights and experiences relating to maternal health, as well as collaborate in developing content for broader questionnaires and focus groups.

In order to identify good practice and key barriers from a service provision perspective, a 'call for evidence' survey aimed at frontline health and care professionals was developed and disseminated via existing networks, including the *Queens Nursing Institute*, the *Gypsy, Traveller, Roma and Boater Network*, and key maternity care organisations, among others. 10 responses were received in total.

Engagement of women and parents from Gypsy, Roma and Traveller communities was conducted via a survey and focus groups. To combat participation barriers relating to digital exclusion, low literacy and language barriers, engagement was conducted flexibly; either face-to-face or over the telephone by frontline workers. Survey respondents totalled 23, including 5 Romany Gypsy, 3 Irish Traveller, 10 New Traveller, 2 Boater and 3 individuals who categorised themselves as 'other'. Respondent ages ranged from 18-64.

Several focus groups were held by FFT, as well as partner organisation RSG. FFT focus group participants totalled 68 individuals, including 29 Romany Gypsy, 21 Irish Traveller, 16 New Traveller, 1 Welsh Traveller and 1 Roma. RSG focus group participants totalled 18 women from the Roma community, 9 Romanian Roma and 9 Polish Roma, aged between 30-55.

Following data collection, engagement sessions were held with the FFT working group and key Gypsy, Roma and Traveller voluntary sector organisations to discuss findings and agree on good practice guidance.

Introduction to Gypsy, Roma, and Traveller communities

The term Gypsy, Roma and Traveller (GRT) encompasses various communities, including Romany Gypsies (English Gypsies, Scottish Gypsy Travellers, Welsh Gypsies, and Romany people more widely), Irish Travellers, New Travellers, Boaters, Showmen and Roma¹. Use of the 'GRT' grouping presents the same issues as the use of '**BAME**', as it arguably fails to reflect the true diversity of the communities referenced. For the purposes of this guide we have avoided its use, however you may find the term used in other policy documents.

Gypsy, Roma and Traveller communities have traditionally lived nomadic lives in the UK, although members of these communities have increasingly moved into bricks and mortar housing. The 2011 census for England and Wales recorded 74% of Gypsies and Travellers as living in houses, flats, maisonettes or apartments.²

The table below offers some basic background information on these groups, and this [video produced by Travellers' Times](#)³ provides a short, animated history of Britain's nomadic communities.

¹ GOV UK (2022) [Gypsy, Roma and Irish Traveller ethnicity summary](#)

² 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?](#)

³ Traveller's Times (2019) [Roads from the Past](#)



	Ethnicity	Arrival in England	Language	Accommodation type
Romany Gypsies	Historically originating in northern India, Romany Gypsies have been in the UK for many generations.	Before the 16th Century.	Romany Gypsies speak English and many also speak a Romani dialect to varying levels of fluency.	Around 75% of Romany people live in housing, and 25% live on Traveller sites, in caravans or chalets, or roadside.
Roma	Historically originated in Northern India and settled in Europe (including Romania, Slovakia, Czech Republic and Poland) before migrating to the UK more recently. Culturally, Roma individuals may belong to any of ~40 different groups/tribes.	Small numbers since 1945, with a number of Roma seeking asylum in the 1990s, and early 2000s, then a growth in population following EU expansion in 2004 and 2007.	The majority of Roma speak one of the many Romani dialects as a first language and their European origin country's as a second language. However the fluency in second language, as well as in English varies greatly.	The vast majority of Roma people live in housing, although there are disproportionate levels of homelessness and overcrowding.
Irish Travellers	Irish Travellers originated in Ireland as a distinct and separate ethnic group from the general Irish population recorded since the 12th century.	Recorded from the 18th century.	Irish Travellers speak English and some speak Gaelic/Irish. Many Irish Travellers also speak Gaelic derived Gammon or Cant.	Around ¾ live in housing and ¼ on Traveller sites in caravans or chalets. Of these, a small proportion live roadside or in public spaces.

	Ethnicity	Arrival in England	Language	Accommodation type
Travelling Showmen	Anyone who travels to hold shows, circuses and fairs can be a Showperson. Many families have led this way of life for generations and many have Romany heritage.	According to the National Fairground Archive the first recorded charter was granted to King's Lynn in 1204.	Showmen primarily speak English.	Most Showmen live on yards in the winter months and travel during the summer months.
New Travellers	'New Traveller' can describe people from any background who chooses to lead a nomadic way of life or their descendants.	The New Traveller movement finds its roots in the free festivals of the 1960s, but people of all backgrounds have practiced nomadism throughout history.	New Travellers primarily speak English.	New Travellers lead a nomadic way of life – in vans, mobile homes, caravans and a small proportion are horse drawn.
Liveaboard Boaters	Anyone who lives on a boat, from all walks of life and backgrounds.	People have been living and working on boats since canals were built in England in the 18th Century.	Liveaboard Boaters primarily speak English.	Boaters live on narrowboats, barges or river cruisers, whether on a home mooring, a winter mooring or continuously cruising on a canal, or in a marina.

In the 2021 UK census, 172,465 people from Romany Gypsy, Roma and Irish Traveller communities in England and Wales disclosed their ethnicity⁴. However, census engagement is negatively impacted by a significant trust gap between Gypsy, Roma and Traveller communities and state institutions, or public services. It is therefore likely that the official census record is an underestimate of the true

⁴ Office for National Statistics (2021) [Ethnic Group \(detailed\)](#)

population size; other data sources estimate the UK's Gypsy, Roma and Traveller population to be in the region of 150,000 to 300,000⁵, or as high as 500,000⁶.

Historically, Gypsy, Roma and Traveller communities have faced persecution across the UK and Europe, with every modern EU state having anti-Gypsy laws at some point. In the 16th century a law was passed in England that allowed the state to imprison, execute or banish anyone that was perceived to be a Gypsy.⁷ Historians estimate that during the Second World War, between 200,000 and 500,000 Roma and Sinti people were murdered by the Nazis and their collaborators in an act known as the Roma Genocide.⁸ Many Roma women were forcibly sterilised when accessing health services across parts of mainland Europe, with the last known case of this as recent as 2007, in the Czech Republic⁹. This history is felt keenly by Gypsy, Roma and Traveller people and contributes to the lack of trust in state structures and bodies.

Today, the UK Government accepts that 'Gypsies, Travellers and Roma are among the most disadvantaged people in the country and have poor outcomes in key areas such as health and education'¹⁰. Gypsy, Roma and Traveller communities are known to face some of the starkest inequalities in healthcare access and outcomes amongst the UK population, including when compared with other minority ethnic groups.¹¹ The reasons for these poor health outcomes are complex, but include the impact of discrimination and stigmatisation, the complicated nature of health systems and the effects of wider social determinants of health. The following report will outline inequalities in health services and health outcomes for maternity care, as well as offering guidance and recommendations for health professionals to help address this.

⁵ Council of Europe (2012) [Estimates of Roma Population in European Countries](#)

⁶ University of Salford (2013) [Migrant Roma in the United Kingdom: Population size and experiences of local authorities and partners](#), p.7

⁷ National Archives, '[Act concerning 'Egyptians'](#), 1530.'

⁸ Holocaust Memorial Day Trust, [The Roma Genocide](#)

⁹ Hutt (2021) [The shameful story of Roma women's forced sterilisation in central Europe](#)

¹⁰ UK Government (2017) [\(GRT0059\)](#)

¹¹ Parry et al (2007) [Health status of Gypsies and Travellers in England](#)

Literature Review

Introduction

The following literature review will contextualise FFT's research within existing studies on maternal health inequalities experienced by Gypsy, Roma and Traveller parents and the key barriers to maternal care experienced within these communities in the UK and Europe. This review will also outline important research gaps relating to these issues and offer anecdotal summaries from FFT's own outreach work.

It should be noted that the 'Gypsy, Roma and Traveller' category and grouping is not in universal use across Europe. Consequently, there is unavoidable variation in authors' use of ethnonyms. For example, authors in Europe may refer to some communities as 'Romany', 'Gypsies' or 'Romani' whereas from a UK policy context we would better understand these communities to be migrant Roma. To avoid misinterpretation, we will remain true to original authors' terminology throughout but will provide clarity where possible.

Health context for Gypsy, Roma and Traveller communities

Members of Gypsy, Roma and Traveller communities have the worst general health outcomes of any ethnic group in the UK.¹² The 2021 census for England and Wales revealed that 14% of Gypsy or Irish Traveller respondents described their health as "bad" or "very bad", more than twice as high as the White British group.¹³ The Race Disparity Audit reveals that Gypsy and Traveller people are less likely to be satisfied with access to a GP than white British people (60.7% compared to 73.8%) and are also less likely to be satisfied with the service they receive (75.6% compared to 86.2% for white British)¹⁴¹⁵. Other research shows that the health status of Gypsies and Travellers is much poorer than that of the general population, even when controlling for other factors such as variable socio-economic status and/or

¹² House of Commons Women and Equalities Committee (2019) [Tackling inequalities faced by Gypsy, Roma and Traveller communities](#)

¹³ Office for National Statistics (2023) [Ethnic group differences in health, employment, education and housing shown in England and Wales' Census 2021](#)

¹⁴ UK Government Ethnicity Facts and Figures, ['Satisfaction with access to GP services.'](#) [These figures should be treated with caution, as sample sizes are small.]

¹⁵ UK Government Ethnicity Facts and Figures, ['Patient experience of primary care - GP services.'](#)

ethnicity¹⁶; life expectancy for Gypsy and Traveller men and women is 10 years lower than the national average¹⁷, and 42% of English Gypsies are affected by a long term condition, as opposed to 18% of the general population¹⁸. Roma communities experience specific social exclusion factors and barriers in access to health and care services¹⁹. Roma individuals also have multiple overlapping risk factors for poor health and a life expectancy up to 10 years less than non-Roma communities in the UK²⁰.

Maternal health inequalities experienced by Gypsy, Roma and Traveller parents

These inequalities are also reflected in Gypsy, Roma and Traveller experiences of maternal health and care. Anecdotal evidence acquired through FFT casework reveals that barriers are present for gaining access to midwifery services and other maternal healthcare, particularly for nomadic parents (for example, a midwife may be unable to visit an expectant parent before they are moved on by a local authority). Gypsy, Roma and Traveller people living in bricks and mortar accommodation may experience comparable barriers, such as finding that language, discrimination, or other structural barriers can limit access to maternal healthcare services.

Research shows that inequalities in preventable maternal mortality and morbidity are greater for minority ethnic parents generally²¹, and focused studies on Gypsy, Roma and Traveller communities have revealed specific inequalities faced by these groups.

United Nations bodies have acknowledged that disparities in access to maternity care and family planning exist for Romani women in Europe²². Romani women in Europe experience higher birth rates among adults and teenagers, higher rates of

¹⁶ Race Equality Foundation (2008) [The health of Gypsies and Travellers in the UK](#)

¹⁷ Equality and Human Right Commission (2017) [Gypsies and Travellers: simple solutions for living together](#)

¹⁸ Royal College of General Practitioners (2013) [Improving access to health care for Gypsies and Travellers, homeless people and sex workers](#)

¹⁹ UK Government (2022) [Improving Roma health: a guide for health and care professionals](#)

²⁰ European Public Health Alliance (2018) [Closing the life expectancy gap of Roma in Europe](#)

²¹ Fernandez Turienzo et. al., (2021) [Addressing inequities in maternal health among women living in communities of social disadvantage and ethnic diversity](#)

²² Colombini et. al., (2011) [Access of Roma to sexual and reproductive health services: Qualitative findings from Albania, Bulgaria and Macedonia](#)

illegal or dangerous abortion services, and significantly higher instances of poor infant outcomes when pregnancy was carried to term.²³ Similar rates of poor infant outcomes were reported for English Romany women (12.8% compared to 6.9% for the general population), although this study is fairly dated, having taken place in 1986.²⁴

In the UK, significantly higher rates of premature death have been reported among children of Gypsy and Traveller parents than the general population²⁵. 1 in 5 Gypsy and Traveller mothers will experience the loss of a child, compared to 1 in a 100 in the non-Traveller community.²⁶ A 2009 study found miscarriage rates to be significantly higher for Gypsy and Traveller mothers, correlating this with reported poor living conditions and offering specific recommendations for improved accommodation provision to tackle this²⁷. In 2019, the House of Commons Women and Equalities Committee reported consistent failure by local and national policy to address health inequalities experienced by Gypsy, Roma and Traveller communities in the UK. The report offered specific recommendations around conducting enquiries and assessments to determine Gypsy, Roma and Traveller health needs and inclusion in health services, improvements for amenities and conditions on Traveller sites, as well as the implementation of training targeted at maternity and pre-natal staff to better support Gypsy, Roma and Traveller women.²⁸

Research shows breastfeeding rates to be low among Gypsy, Roma and Traveller communities. Small-scale studies show that breastfeeding rates are extremely low among English and Welsh Gypsies, and Scottish and Irish Travellers, with one study finding a breastfeeding initiation rate of 3%, with none continuing to six weeks²⁹. For many Gypsy, Roma and Traveller communities breastfeeding may not be typical and

²³ Watson and Downe (2017) [Discrimination against childbearing Romani women in maternity care in Europe: a mixed-methods systematic review](#)

²⁴ Pahl and Vaile, (1986) [Health and health care among Travellers](#)

²⁵ Parry et al (2007) [Health status of Gypsies and Travellers in England](#)

²⁶ Ormiston Children and Families Trust and Cambridgeshire Community Services (2008) [An Insight into the Health of Gypsies and Travellers: A Booklet for Health Professionals in Cambridgeshire](#)

²⁷ Pahl and Vaile (2009) [Health Care Among Travellers](#)

²⁸ House of Commons Women and Equalities Committee (2019) [Tackling inequalities faced by Gypsy, Roma and Traveller communities](#) p. 62-63.

²⁹ Pinkney (2011). ['The infant feeding practice of Gypsy and Traveller women in Western Cheshire Primary Care Trust and their attitudes towards breast and formula feeding.'](#)

can be viewed by some as an ‘immodest act’³⁰. However, breastfeeding rates are much higher among European Roma communities, where breastfeeding is the cultural norm, with some mothers going as far as to describe the practice of breastfeeding as being an integral part of their cultural identity as Roma mothers³¹. Breastfeeding may be more common among Roma communities, but would typically be considered a very private process.³²

Research also indicates that Irish Traveller parents may be more susceptible to some metabolic ailments, including Classical Galactosemia. Approximately one in every 19,000 infants born in Ireland may have this condition, however, it is particularly common among infants born to Irish Traveller parents in whom the incidence is approximately 1 in 450 births compared to 1 in 36,000 births among the non-Irish Traveller, Irish community³³. If infants with Classical Galactosemia are not treated promptly with a low-galactose diet, life-threatening complications appear within a few days after birth³⁴.

Key maternal health statistics

- **Gypsy and Traveller mothers are 20 times more likely** than the general population to experience the premature death of a child.³⁵
- **29% of Gypsy and Traveller parents are likely to experience one or more miscarriages** (compared to 16% among the non-Traveller comparator group surveyed).³⁶
- **Roma mothers experience higher rates of poor infant outcomes**, such as preterm births and low birthweight, than the non-Roma population.³⁷

³⁰ Condon & Salmon (2014). [“You likes your way, we got our own way”: Gypsies and Travellers’ views on infant feeding and health professional support.](#) Health Expectations

³¹ Condon (2015) [Roma, Gypsies, Travellers and Infant Feeding](#)

³² Condon & Salmon (2014). [“You likes your way, we got our own way”: Gypsies and Travellers’ views on infant feeding and health professional support.](#) Health Expectations

³³ Health Service Executive (n.d) [Classical Galactosemia](#)

³⁴ MedlinePlus (n.d) [Galactosemia](#)

³⁵ Equality & Human Right Commission (2017) [Gypsies and Travellers: simple solutions for living together](#)

³⁶ Parry et. al. (2007) [Health status of Gypsies and Travellers in England](#)

³⁷ Watson and Downe (2017) [Discrimination against childbearing Romani women in maternity care in Europe: a mixed-methods systematic review](#)

- **Classical Galactosemia is particularly common among infants born to Irish Traveller parents:** the incidence is approximately 1 in 450 births, compared to 1 in 36,000 births among the non-Irish Traveller, Irish community³⁸. If not treated promptly, life-threatening complications can appear within a few days after birth³⁹.

Key barriers to maternity care

There are a number of studies addressing the barriers Gypsy, Roma and Traveller parents may experience when attempting to access maternal care. Maternity Action interviewed a number of Gypsy, Roma and Traveller women who reported feeling that discrimination limited their ability to access care. Participants reported that language level was a significant barrier in accessing care, with a number of women reporting that they felt a shift in staff willingness to help once it became clear that English was not a first language.⁴⁰

Existing research also positions language as a key barrier for Romani women in Europe when accessing maternity care; other barriers include a lack of awareness of Romani right to care, geographic and/or transport barriers, financial barriers and discrimination barriers.⁴¹

Barriers to accessing maternal care for Gypsy and Traveller communities are not as well-represented in the literature. However, it is noted across Gypsy and Traveller health literature broadly that several barriers are known to play a part in access disparities for these communities (for example, difficulty accessing primary care services, low or no literacy, experiences of discrimination, poor continuity of care and

³⁸ Health Service Executive (n.d) [Classical Galactosemia](#)

³⁹ MedlinePlus (n.d) [Galactosemia](#)

⁴⁰ Maternity Action (2018): [Mothers' Voices - Exploring experiences of maternity and health in low income women and children from diverse ethnic backgrounds](#)

⁴¹ Watson and Downe (2017) [Discrimination against childbearing Romani women in maternity care in Europe: a mixed-methods systematic review](#)

poor cultural awareness among frontline staff)^{42,43,44,45}. These are very likely to pose similar barriers when considered in the context of maternal care, and FFT's anecdotal evidence drawn from support work shows that continuity of care for nomadic mothers is difficult to establish given the frequency of eviction.

Key Barriers Summary:

- **Communication and cultural barriers:**
 - *Issues with language or literacy, lack of staff awareness around patients' cultural needs.*

- **Accommodation and transport barriers:**
 - *Patients may be unable to reside in one place long enough to receive maternal care, may be unable to afford to travel to seek maternal care.*

- **Administration and support barriers:**
 - *Patients may have low or no literacy, be unable to provide appropriate documentation, or be unaware that they are entitled to care.*

- **Discrimination barriers:**
 - *A clear trend in the literature indicates that patients from all communities believe that discrimination plays a significant role in their experience of care.*

Overview of research gaps

The Literature Review process made clear that existing research on Gypsy, Roma and Traveller experiences in healthcare is relatively limited, with even less research available that specifically addresses maternal care. FFT's review of the literature also found that research available on Gypsy, Roma and Traveller experiences in maternity care, particularly in the UK context, relied on a relatively small pool of

⁴² Friends, Families & Travellers (2021) [Locked Out: 74% of GPs refused registration to nomadic patients during COVID-19 Pandemic](#)

⁴³ Hudson (2009) [Hearing the human rights voices of Gypsy and traveller mothers in the UK](#)

⁴⁴ Cleemput (2010) [Social exclusion of Gypsies and Travellers: health impact](#)

⁴⁵ Rogers and Greenfields (2017) [Hidden losses and 'forgotten' suffering: the bereavement experiences of British Romany Gypsies and Travellers](#)

authors, indicating that this topic may be of specific interest to select researchers but lacks broad study or attention.

In the 2017 systematic review by Watson & Downe, the authors noted a relatively small body of knowledge to draw from in regard to maternal healthcare for Romani women in Europe⁴⁶. With the inclusion of grey literature and qualitative studies, the authors did conclude in their review that access disparities to maternal healthcare do exist for Romani women (and these result in part from failures to deconstruct barriers existing at the policy level). Similarly, the April 2019 House of Commons Women and Equalities Select Committee report on inequalities faced by Gypsy, Roma and Traveller communities noted that there was a significant lack of data in the UK context⁴⁷.

Within UK publications relating to policy and recommendations, the inclusion of Gypsy, Roma and Traveller parents was limited, and often did not appear to reflect the diversity and extent of barriers otherwise suggested by the literature. Often, inequalities were acknowledged without offering meaningful recommendations for change. Previous FFT research⁴⁸ found that the majority of Joint Strategic Needs Assessments, Joint Health and Wellbeing Strategies and Suicide Prevention Plans contain no mention of Gypsy, Roma and Traveller communities. Even fewer identify any positive actions to tackle the health inequalities faced by these people from these communities.

While a number of studies and reports refer to poor living conditions and/or lack of access to infrastructure, rarely do any of these go into specific detail about these conditions or which infrastructure is missing – for example, environmental factors, lack of amenities or running water, electricity and/or overcrowding. This makes it difficult to determine which living conditions are correlated with poorer outcomes for Gypsy, Roma and Traveller mothers.

⁴⁶ Watson and Downe (2017) [Discrimination against childbearing Romani women in maternity care in Europe: a mixed-methods systematic review](#)

⁴⁷ House of Commons Women and Equalities Committee (2019) [Tackling inequalities faced by Gypsy, Roma and Traveller communities](#)

⁴⁸ Friends, Families & Travellers (2015) [Inclusion of Gypsy Traveller health needs in Joint Strategic Needs Assessments: A review](#)

Another issue within existing literature was an inconsistency in terminology and grouping. In studies focused on European Romani people, authors identified participants variously by nationality, ethnicity, or cultural grouping (for example 'Slovakian', 'Roma/Sinti/Romani', or 'Kalderash Roma'). Similar issues were noted for studies conducted in the UK, where authors variously categorised participants as English, Irish, Gypsy-Travellers, Gypsy/Traveller, or separately as Romany Gypsies and Irish Travellers. Unless aggregated without being noted, there was little to no mention of other UK communities such as New Travellers, Showmen, Scottish Gypsy-Travellers communities (who are known to experience inequalities). These inconsistencies in grouping and identification make it difficult to rely on the literature for precise recommendations, despite an obvious trend in the literature that suggests specific communities may at times benefit from special considerations in maternal care (for example, in the case of predisposition to metabolic ailments).

Rates of Caesarean birth were unusually high among Gypsy, Roma and Traveller participants for this study, and a maternity professional survey respondent also flagged this as a notable trend among Gypsy, Roma and Traveller patients. There is very little published data available on rates of Caesarean birth disaggregated by ethnicity in the UK, with no published research conducted into the experiences of Gypsy, Roma and Traveller communities specifically. Some research has been conducted relating to disparities in Caesarean birth based on ethnicity in the United States, indicating higher rates of Caesarean birth among women who identify as being from racial/ethnic minorities.⁴⁹

These gaps and inconsistencies highlight the need for direct engagement and communication with Gypsy, Roma and Traveller communities by healthcare providers and policymakers, in order to build a clearer understanding of community requirements, locally and nationally. FFT's direct work with Gypsy, Roma and Traveller communities provides anecdotal evidence and experiences, which inform and guide our work.

⁴⁹ [Eliner et al \(2022\) Maternal education and racial/ethnic disparities in nulliparous, term, singleton, vertex cesarean deliveries in the United States](#)

Anecdotal summaries

FFT's outreach work allows for the inclusion of anecdotal observations on the experiences of Gypsy, Roma and Traveller communities supported by the organisation, as summarised below:

- **There can be a lack of trust among Gypsy, Roma and Traveller communities** around state services, including health and maternity care.
- **There is a lack of support from local authorities for expectant Gypsy, Roma and Traveller parents**, even with ensuring provision of running water or sanitation amenities.
- **Continuity of care for nomadic parents is low.** There are many challenges associated with securing and/or attending appointments with maternity care providers, and further difficulties establishing relationships of trust with providers.
- **Conditions such as pre-eclampsia and postpartum depression may go undiagnosed among Gypsy, Roma and Traveller communities** due to inconsistent care, among other factors.
- **Unusually high rates of Caesarean births** are reported by Gypsy, Roma and Traveller parents.
- **Gypsy, Roma and Traveller parents, without dedicated maternity care advice, may rely on outdated or historic advice** meaning children do not benefit from advances in medical knowledge and care.
- **Poor cultural awareness can lead to misunderstandings.** For examples, the discussion of pregnancy is a taboo, which may lead to healthcare workers believes there is an unwillingness to engage or receive care.
- **Maternity care providers may be reluctant to give advice that is essential for nomadic parents.** For example, co-sleeping is typically discouraged by

care providers, but nomadic parents in confined spaces may have little alternative.

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 generally⁵⁰. Large percentages of Roma communities across Europe are reported to be effectively or functionally illiterate⁵¹, data which corresponds to the anecdotal evidence of Roma Support Group staff experiences.

⁵⁰ [Liegeois and Gheorghe \(1995\); Fraser \(1995\); Levinson \(2007\); Greenfield et al. \(2007\)](#)

⁵¹ [European Union Agency for Fundamental Rights \(2014\). Roma survey – Data in focus Education: the situation of Roma in 11 EU Member States](#)

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:

“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 English⁵². 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).⁵³

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

⁵² Roma Support Group (2022) [Language barriers and communication](#)

⁵³ Roma Support Group (2022) [Language barriers and communication](#)

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 usage⁵⁴.

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.⁵⁵

Roma people also experience high levels of digital poverty, lacking adequate technology and equipment such as smartphones and laptops⁵⁶. A lack of digital skills

⁵⁴ Friends Families and Travellers (2018) [New report reveals significant digital exclusion in Gypsy and Traveller communities in the UK](#)

⁵⁵ Friends Families and Travellers (2018) [New report reveals significant digital exclusion in Gypsy and Traveller communities in the UK](#)

⁵⁶ Lawforlife (2021) [Digital exclusion and Roma communities in the context of child protection](#)

to engage with the internet and other digitised platforms also prevents Roma people from engaging in a meaningful way⁵⁷.

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:

Tackling issues around communication and accessible information within maternity is crucial. Recommendations based on data gathered include:

- **Ensure resources are tailored** to the patient's level of literacy.
- **Ensure staff and care providers are trained in the practicalities of working with patients with low or no literacy**, as well as those with limited vocabulary.
- **Best practice for interpreting would include working with bilingual Roma advocates**, who are ideally able to communicate in the patient's first language.
 - Interpreters should be instructed to thoroughly explain concepts, rather than simply directly translating medical terms, for example, to ensure that patients have fully understood.
 - Interpreters should also routinely confirm with patients that they have fully understood all information provided.
- **Produce information for distribution by GPs in community languages**, that explain the pregnancy care pathway, including which professionals are involved and the reasons behind common practices.
- **Ensure resources are designed with cultural sensitivity.**

⁵⁷ Lawforlife (2021) [Digital exclusion and Roma communities in the context of child protection](#)

- *Be aware that images of genitals may be culturally inappropriate in some contexts. Consider renaming breastfeeding as natural feeding, for Roma communities (see more in Theme 5).*
- **The Secretary of State for Health and Social Care should make a clear commitment** to ensure that patients who choose to access health services through non-digital means should be able to access all NHS healthcare settings.
- **NHS England should introduce contractual obligations for GP practices** to allow patients to through non-digital means if they chose, unless there are good clinical reasons to the contrary.
- **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.

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.⁵⁸

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.

⁵⁸ Friends, Families & Travellers (2019) [No room at the inn: How easy is it for nomadic Gypsies and Travellers to access primary care?](#)

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 diminished⁵⁹. 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 chronic national shortage of sites, and 3,000 families without a permitted stopping place have limited or no access to basic water and sanitation.⁶⁰ 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.

⁵⁹ The Marmot Review (2010) [Fair Society, Healthy Lives](#)

⁶⁰ MHCLG (2019) [Traveller caravan count: January 2019](#)

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 are never wrongfully refused registration; patients are entitled to use a temporary or ‘care of’ address when registering.
 - Drop-in services, same-day appointments, and flexible timing around sessions can help make services more accessible.
 - Local PCNs can assess how successfully they are engaging with Gypsies, Roma and Travellers, and other inclusion health groups [here](#).
- **Ensure patients facing digital exclusion are able to book appointments:**
 - Booking options over the phone, online or in person can help to address this.
- **Collecting data on the wider determinants of health for patients can help tailor services.**
 - As part of registration procedures, patients could be asked about factors that might impact their experience of care.
e.g. “Are there any things that it may be helpful for us to know about which may affect your health, wellbeing, or experience of care? This may include that you lead a nomadic way of life and might be moving between service areas...”
- **Consider how your service can support the wider determinants of a patient’s health.**
 - The approaches to evictions of roadside camps need to consider the maternal health needs of individuals. Consider how you can ensure that nomadic patients are not evicted whilst pregnant or living with children, or how to ensure patients do not miss out on continuity of care while travelling. This may require collaboration with local authorities or volunteer sector organisations.

- **NHS England should create a clear information resource for clinicians** on responsibilities to nomadic people.
- **NHS England should work in partnership with voluntary sector organisations and nomadic communities** to create and disseminate clear information for nomadic patients on their rights to healthcare, in particular elective care and screenings when travelling and where to go for support when they are denied.
- **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, with clear actions across Government to address these stark inequalities.
- **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. This should be a key aspect of all equality impact assessments and decision-making, in line with Public Sector Equalities duties.
- **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**, assessing issues around access within their area.
- **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.⁶¹

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/or 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.”

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

⁶¹ Equality and Human Rights Commission (2018) [Developing a national barometer of prejudice and discrimination in Britain](#)

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 policies relating to 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.

- **Participants felt that Drug & Alcohol Specialist midwives should be renamed as “Inclusion Health Midwives”**, so that people understood that there may be variety of reasons someone would be visited by them.
- **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.

- Some professional survey respondents referenced local GPs who support with managing waiting lists and provide regular check-ins for Gypsy, Roma and Traveller patients wherever they are in the country. Such measures help to build a relationship of trust, which begins with learning about the cultures and needs of patients.
- **Carefully review all referrals to social services.**
 - Referrals to social services must be handled with extreme care; concerns should be communicated openly and sensitively to the patient.
- **Understand that reticence around home visits may be anchored in concerns about negative perceptions of nomadic living, or insecure housing.**
 - Ensure care providers are trained in the norms and traditions of nomadic living.
 - Some Roma patients may live in insecure and/or shared accommodation, without formal tenancy agreements, which can lead to fears around home visits. This is often linked to patients not fully understanding the role of home visitors, thinking of them as inspectors.
 - When communicating with patients, emphasise that home visits are not inspections but are intended to provide support.
- **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 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.⁶²

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:

⁶² Roma Support Group (2022) [Maternity Services](#)

“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.

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.**
 - Gypsy, Roma and Traveller communities have knowledge and experience which can complement and enhance that of health care professionals.
- **Ensure that Roma women observing the post-partum 'purity period' are not excluded from postnatal care.**
 - Offer cultural training on the 'purity period' for GPs, midwives, maternity/perinatal health services and health visitors, and consider an increase in home visits and home vaccinations if women stay at home for the first one to three months postpartum.
 - Understand that the father not being present during this time is culturally appropriate in Roma communities and not a safeguarding concern of 'abandoning the family' or similar.

- Provide women after the birth with information they can use during the postpartum 'purity period', e.g. on preventing cot death, breast feeding, heel prick test and first bath for the baby.
- **Explain in advance and then again at the time what home visits will be about and what will happen**, including potentially examining bodily areas traditionally regarded as taboo. Explain to the family what will happen on any health visit, and the need for private conversation / instructions that may involve touching.
- **Consider who else is in the room when conversations are held** and ensure that the patient feels comfortable speaking openly.
 - It may not be suitable for family members or friends of other genders or generations to be present with the patient when discussing health topics.
 - Periods and obstetric and gynaecological conditions are considered deeply private matters and may not be appropriate to be discussed even with other women present in the room.
- **Ensure official interpreters are used.**
 - Do not use children or other family members as interpreters, especially when relating to gynaecological matters. Interpreters should be booked by the healthcare provider instead of requesting the patient to provide their own.
- **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.
 - Antenatal care may be assumed to be curative rather than preventative, and there may be a need to explain in more depth the need for screening and scans.
 - Work with community organisations to hold Q&A sessions on maternity care for Roma women with female practitioner nurses in community venues.

- **Be aware that breastfeeding may be an uncomfortable topic** for some patients from Gypsy, Roma or Traveller communities.
 - Consider that some people wanting to breastfeed may not feel comfortable doing so in front of others, regardless of gender.
 - Respect the patient's wishes. Provide accessible, non-judgemental advice on all feeding options, so that patients are able to make their own informed choices.
 - Do not automatically latch on a new-born without discussing this and asking the patient's consent.
 - Early, inclusive and accessible conversations prepartum informing about the advantages of breast feeding can have positive outcomes on postpartum breast feeding.
 - For some patients (particularly within traditional Roma groups) it may be appropriate to refer to breastfeeding as 'infant feeding', as references to intimate body parts can be taboo.

- **Cater for postpartum depression in a culturally sensitive manner.**
 - Understand that there may be a reluctance to admit to the need for help with post-partum depression due to taboos about mental health.
 - This can also contribute to a lack of awareness about perinatal mental health symptoms and signs.
 - There may be a lack of awareness of mental health services, so emphasise the availability of these services before they are needed.
 - Distrust of healthcare professionals can lead to women and their families being reluctant to disclose mental health issues, or that they need support.

- **Produce and distribute accessible and culturally relevant resources and education** on perinatal mental health.
 - Whole population approaches to prevent poor mental health should be accessible for people with low literacy, low English fluency, and those who are experiencing digital exclusion.

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.
 - Ensure that all the criteria are met for Caesarean birth and ensure that the patient has fully understood all the information, in order to be able to inform those involved in any subsequent births.

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.** Careful, sensitive questioning around this topic when getting to know a new patient can be useful in understanding patient history and identifying specialised support needs.
 - For example, early screening questions from care providers might include “How many pregnancies have you experienced?” as well as “Do you have any children?”
- **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.
 - When working with patients, it’s important to be aware of the potential for unresolved trauma or distress from previous experiences.
 - It is crucial to sensitively discuss these topics, to ensure that patients are aware of what support is available and how they can access it.
- **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.

- a. Consider that a lack of knowledge of the UK health system may lead to confusion about which services should be accessed at which time during the maternal health journey. Ensure that it is clear who will be providing care at each stage of the maternal care pathway and where this care will be taking place.

2. Work collaboratively with voluntary and community organisations.

- a. Working with community organisations can provide a culturally aware link between patients and the health service. View FFT's [Services Directory](#) for further information on specialist services for Gypsy, Roma and Traveller communities around the country.
- b. For example, RSG provide a culturally aware link between clients and the health service, and a space where clients feel safe discussing mental health problems because they know the adviser and the organisation very well.
- c. FFT have also specifically attended mental health appointments with clients to ensure the community member understands the information that is being given to them in a culturally pertinent way, to overcome stigma and to provide one-to-one support, while managing expectations of the service.
- d. 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. This includes open access to medical notes, signposting to culturally appropriate support to navigate access to mental health provision. In addition, there need to be systems in place for continuity of care and extra support in subsequent pregnancies.

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 roadside.

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

- a. A direct recommendation from Gypsy, Roma and Traveller groups consulted by FFT and RSG is to increase the representation of Gypsy, Roma and/or Traveller staff in health services, in order to help build trust and ensure that 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. Working closely with experts by experience to research what the communities want and need is imperative to creating impactful support. The key to success is making sure people from Gypsy, Roma and Traveller communities are 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 a greater understanding of population size of Gypsy, Roma and Traveller communities in your area. You could draw from [2021 Census Data](#), Gypsy and Traveller Accommodation Needs Assessments (GTANAs), [Department for Education data](#) or the [Ministry of Housing, Communities and Local Government Traveller Caravan Count](#). Bear in mind that much official data is considered an undercount, since many Gypsy, Roma and Traveller individuals are unwilling to disclose their identity or face barriers to participation in data collection.